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The Meanings of the 'Struggle/Fight Metaphor' in the Special Needs Domain:

The Experiences of Practitioners and Parents of Children with High Functioning Autism Spectrum Conditions

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Doctor of Philosophy

University of Sussex

January 2013

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Acknowledgments

This thesis would not exist without the parents and practitioners who agreed to share their stories with me - a heartfelt thanks to each of you for risking your story with me!

I also want to thank the many people who have accompanied me on different parts of the journey:

Judith Good and Susie Scott who have helped me to play by the rules – thank you for your patience and persistence and for keeping me on track;

Lou McGill, my critical friend;

Friends and colleagues at the University of Sussex, too numerous to mention by name, but the folk who have met for breakfast, or coffee, or cream tea;

The network of research students who inhabit Twitter and #phdchat, the folk who have so often picked me up and supported me when I've threatened to jump ship;

My colleagues at The Open University, some of whom commented on initial drafts and diagrams, and my managers who supported my application for financial support.

And most of all thanks to my husband, friend, confidant and proof reader – thank you Gordon for putting up with all the mood swings – and to my son, who because of who he is, got me involved in the special needs domain.

Thanks are also due to Taylor and Francis Group for permission to reproduce the diagram 'The three domains of the SEN system' originally published in the European Journal of Special Needs Education, vol 23, issue 4, page 373, and to The Open University for permission to reproduce the diagram 'Four phase cycle of enquiry'.

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Liz Thackray

Doctor of Philosophy

The Meanings of the 'Struggle/Fight Metaphor' in the Special Needs Domain: The Experiences of Practitioners and Parents of Children with High Functioning Autism Spectrum Conditions.

Summary

The special needs domain has long been recognised as problematic and adversarial. Much research has focused on areas of contention, such as the relationships between parents and practitioners, especially in educational settings, or on problems within the structure and operation of the domain. This study adopts a whole system approach in combining discussion of the structural basis of tension within the domain with an investigation of how both parents and practitioners describe, experience and respond to tensions within the special needs domain; such tensions being viewed as facets of the 'struggle' and 'fight' metaphor.

Whole systems approaches are derived from the systems discipline, which developed initially out of the nineteenth century interest in organic and engineering systems, but more recently has focused on organisational and inter-organisational arrangements, including the part people play in enabling or disabling such arrangements. It is a strongly interdisciplinary approach more commonly found in organisational studies than in the social sciences more generally.

Fifteen practitioners, from health and education settings, and twelve parents of children and young people with diagnoses of high functioning autism spectrum conditions participated in the study. The participants' stories of their experiences of the special needs domain were collected using a narrative inquiry approach. The data was analysed using concepts and theoretical frameworks derived from the work of Pierre Bourdieu, Uri Bronfenbrenner and Charles Wright Mills.

An exploration of the influences shaping the special needs domain revealed a number of areas of unresolved tension, some of which result in tensions for those involved in the domain such as can be described as 'fight', and some of which might be addressed by structural changes to the systems comprising the special needs domain such as those envisaged in forthcoming legislation. However importantly the empirical study found that many tensions and struggles experienced by both parents and practitioners did not emanate from the structures of the domain and therefore were unlikely to be amenable to structural

changes. Parents 'struggle' to maintain their identity as 'good' parents, to acquire information and to navigate the system in order to access services and resources. Practitioners experience conflict as they seek to access information and training, engage in the complex choreography of cooperating and collaborating in interagency and interprofessional working and endeavour to harmonise their professional practice with agency and public policy priorities.

The thesis concludes with a brief discussion of the relationship between whole system approaches and other interdisciplinary approaches to investigating complex problems in the human sciences. It is suggested that systems diagramming techniques such as systems mapping and rich pictures are useful additions to the sociologist's toolkit.

Abbreviations

ABA	Applied Behaviour Analysis
ADHD/ADD	Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder
ASC or ASD	Autism Spectrum Condition or Autism Spectrum Disorder. In recent years, there has been a move towards greater usage of ASC, but ASD continues to be used in the diagnostic guidelines in the UK (NICE, 2011)
AS	Asperger's Syndrome
BESD	Behavioural, Emotional and Social Difficulties
CAF	Common Assessment Framework
CAMHS	Child and Adolescent Mental Health Services
CDC	Child Development Clinic
CDT	Child Development Team
DLA	Disability Living Allowance
EHCP	Education, Health and Care Plan as proposed in the SEN Green Paper (DfE, 2011)
ESRC	Economic and Social Research Council
GST	General Systems Theory
HFA	High Functioning Autism
IEP	Individual Education Plan
LSA	Learning Support Assistant
MMR	The combined vaccine that protects against measles, mumps and rubella
NAS	National Autistic Society
NICE	National Institute for Health and Clinical Excellence
ODD	Oppositional Defiant Disorder
Ofsted	Office for Standards in Education, Children's Services and Skills
Post-Blair project	ESRC funded investigation "Does Every Child Matter Post-Blair? The interconnections of disabled childhoods" (Goodley et al., 2011)
SEN	Special Educational Needs
SENCo or SENCO	Special Educational Needs Coordinator – the abbreviation 'SENCo' has been used in preference to 'SENCO' throughout this thesis, following (Runswick-Cole, 2007a), but both terms are commonly seen in practice.
SENDisT or SENDIST	Special Educational Needs and Disability Tribunal, which was replaced by the Tribunals Service from November 2008, but the abbreviation continues to be found in practice. The abbreviation 'SENDisT' has been used in preference to 'SENDIST' throughout this thesis, following (Runswick-Cole, 2007a).
SLT	Speech and Language Therapist
SLC	Speech, Language and Communication
SSM	Soft Systems Methodology – a systems approach developed during the 1980s by Peter Checkland
TA	Teaching Assistant – alternative title for Learning Support Assistant
TAC	Team around the Child
TAF	Team around the Family

TLRP   Teaching and Learning Research Programme
UPIAS   Union of the Physically Impaired Against Segregation

A note on the terminology

The term 'special needs' is used throughout to refer to the special needs domain, differentiating this from 'special *educational* needs' or SEN, which is used in the context of school and education settings and when referring to the formal assessment of SEN.

The term 'practitioner' is used to refer to all those who work with children with special needs and their families. I do not differentiate those with professional or other qualifications from those without, recognising the skills, knowledge and expertise of those without formal qualifications who support children with special needs. The term 'professional' is commonly used in statutory documents and by other authors and has been retained when quoting directly from such texts.

The words 'field' and 'system' can have different meanings in everyday language and in academic writing, and the meaning can vary between disciplines. For clarity, following Grenfell (2004), I adopt the practice of *italicising* these terms when they are used in their technical or theoretical sense, retaining their everyday meaning elsewhere.

Preface

In 1980, I was employed as the voluntary organisations liaison officer in the Social Services Department of an inner London borough. One day my manager informed me the following year would be the International Year of Disabled People. As the borough I was employed in was one of only two London boroughs not to have a disability association, this would be an ideal opportunity to explore the possibility of establishing one. During the following months, as I met representatives from various organisations working with disabled people, I became increasingly aware of the beginnings of a move from a paternalistic attitude, where things were done *for* disabled people, to recognising that disabled people were more than capable of taking responsibility for their own lives and affairs. This change in perspective was captured in the constitution of the disability association launched in the borough where I worked and I explored some of the implications of disability associations being organised *by* or *for* disabled people in my Masters thesis (Thackray, 1983).

Some fifteen years later, it became apparent that my son was developing differently from most of his peers. Over a period of several years, he underwent many assessments resulting in diagnoses of ADHD, dyslexia and Asperger's Syndrome. During this period, as I negotiated support for my son, I used online forums to learn from and support other parents who were involved in similar negotiations in different parts of the UK. I was acutely aware that my background had equipped me for this task in that I knew something of how public bodies operated and I had some familiarity with the technical language used by practitioners in various education, health and social care settings. I was equally aware that some of the parents I was in contact with struggled in their negotiations, possibly due to this being an unknown terrain for them, but I also observed parents moving over time from being supported to supporting others. About ten years ago, together with other parents of children with 'special needs', I established a local support group for parents whose children either had 'special needs' or who were concerned their children were developing differently, and I continue to facilitate this group. The underlying principle of this group is one of parents gaining knowledge they can use to support their own child(ren) and also to support other parents.

My experience with my son and with other parents has motivated me to undertake the exploration described in this thesis. In undertaking this work, I become part of a growing group of parents (Marrable, 2011; Rogers, 2007; Runswick-Cole, 2007a; Ryan, 2010) who have melded personal experience and academic research in seeking a better understanding of the complexities of the special needs domain.

Chapter One – Introduction

This study presented in this thesis explores the 'struggle/fight' metaphor in the special needs domain. Many other researchers have investigated problematic areas in the special educational needs (SEN) system, but less attention has been given to the broader special needs domain. Despite many examples of collaborative practice and partnership in the domain, it continues to be viewed and experienced by parents as adversarial. In this study, I adopt a whole *system* approach to investigate the experience of those working with and/or parenting children and young people with high functioning autism spectrum conditions or Asperger's Syndrome (referred to as AS/HFA throughout the thesis) with the aim of arriving at a more nuanced understanding of the tensions experienced within the domain. There remains scope for research focusing on collaborative practices, but that is not the focus of this study.

In March 2011 the UK coalition government published a Green Paper entitled "Support and Aspiration: a new approach for special educational needs and disability" (DfE, 2011), followed in September 2012 by draft legislation that, if enacted, will reform the special education system in England[1]. This consultation document describes the current special educational needs (SEN) system as "bureaucratic, bewildering and adversarial" (DfE, 2011, p. 4) and "no longer fit for purpose" (DfE, 2011, p. 15). The SEN system, as we now know it, has its roots in the recommendations of the Warnock Committee (DES, 1978) as enacted in the 1981 Education Act (HM Government, 1981). Almost since its inception, the SEN system has been subject to criticism (Lewis & Vulliamy, 1980), this criticism increasing in recent years and recognised in a number of government inquiries and reviews (Bercow Report, 2008; House of Commons Education and Skills Committee, 2006; Lamb Inquiry, 2009; Ofsted, 2010; Salt, 2010).

Concern about special needs provision is not limited to the SEN system, which focuses primarily on the assessment and support of children and young people with special needs in educational settings. There is evidence of disquiet about the broader special needs domain in the discourses of parents and practitioners in public online forums and blogs and in publications written for a general audience (for example, Power, 2010; Row, 2005). It is unclear whether the proposed changes to the SEN and disability system can or will address these difficulties and concerns.

In this thesis, I explore the nature of 'struggle' and 'fight' in the special needs domain from a whole *system* perspective. I understand 'struggle' and 'fight' to encompass the range of

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[1] The legislation and formal assessment system and provision for children assessed as having SEN or Disability vary between the nation states of the UK. In Scotland, the Additional Support for Learning (Scotland) Act 2004 was

tensions experienced by those working with and/or parenting children and young people with special needs. Some tensions are overtly adversarial and can be described as 'fight', while others are stressful but do not result in conflict and can be described as 'struggle'. I ask why systems predicated on principles of collaboration and partnership are viewed and experienced as adversarial and can be viewed as a site of struggle. The investigation is undertaken from two viewpoints. Firstly, I consider the structure and functionality of the special needs domain, focusing on the development of the SEN system, identifying the influences that have shaped the SEN system and the domain, and asking how these elements contribute to the perception of the special needs domain as a site of struggle and fight. Secondly, I focus on that part of the domain concerned with children and young people with high functioning autism spectrum conditions (referred to throughout this thesis as AS/HFA[2]) and explore the experiences of struggle and fight as narrated by those who work with or parent children with AS/HFA. In my analysis and discussion, I draw connections between the structural and experiential aspects of struggle and fight and suggest that much of what can be described as struggle and fight originates and remains outside the formal systems comprising the special needs domain, with the implication that changes to the formal structures and systems of the special needs domain may have little or no affect on many of the tensions within the domain.

In examining the tensions present in the special needs domain, I use the expression 'struggle/fight metaphor' as a generic descriptor of the problems encountered at both a domain level and by individuals. It is important to understand what meanings attach to the 'struggle/fight metaphor', especially at a time of change when change is driven, at least in part, by the aim of making the domain less adversarial. Although some factors leading to use of the metaphor may be ameliorated by the outcomes of the SEN review, it is possible others will be unaffected. Equally, there may be aspects of situations giving rise to use of the 'struggle/fight metaphor' that are unaffected by changes in SEN and disability legislation, but may be affected, positively or negatively, by changes in other legislation affecting the special needs domain, such as recent legislation relating to the National Health Service (HM Government, 2012a) and the introduction of the Universal Benefit (HM Government, 2012b). Understanding the breadth and nature of current problems in the domain can assist in understanding any unintended consequences that result from legislative changes affecting the domain. It can also assist in identifying problem areas that are unaffected by legislative and systemic change, but may be addressed in other ways.

In the remainder of this chapter, I introduce the special needs domain and discuss my choice of terminology before stating the specific questions addressed by this research and outlining my methodological approach. I explain why my enquiry focuses on that part of the domain

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[2] All acronyms and abbreviations used in this thesis are listed in the list of abbreviations at the front of the thesis as well as being written in full on first usage in the text.

concerned with AS/HFA and discuss the relevance of metaphors. Finally, I outline the thesis structure, providing a guide to the chapter contents.

The special needs domain

I use the term 'special needs domain' to refer to the various systems, support services and resources that support children identified as having special needs, as distinct from the SEN system, which is primarily concerned with the education of children and young people with special needs. The special needs domain is not coterminous with the SEN system, but the SEN system forms an influential part of the special needs domain. The domain is important because of its size and complexity. It is comprised of parts of the statutory education, health and social care services, voluntary and community services, the extended families and friendship networks of children with special needs and private sector provision in the form of specialist independent schools, private medical practitioners, independent therapists and legal services. Some parts of the special needs domain are highly regulated by statutory controls and professional codes of practice, while others are less regulated or effectively non-regulated. Some parts of the domain are long established while others are temporary by nature. Although the special needs domain, as defined here, relates to children with special needs, as children grow into adulthood, they may require ongoing financial assistance, support in living independently and additional resources to enable access to training, further education and employment. Issues that remain unresolved in childhood may become a charge on the public purse in adulthood.

The government review of the SEN system focuses on formal systems and processes and is driven in part by the acknowledgment that it is a system

> …where parents feel they have to battle for the support they need, where they are passed from pillar to post, and where bureaucracy and frustration face them at every step (DfE, 2011, p. 2).

While giving attention to aspects of special needs that lie beyond the educational system, such as multiple assessments, the SEN Green Paper (DfE, 2011) retains a primary focus on education and educational achievement. It pays scant regard to areas of tension falling outside the formal system, lending weight to a need for further empirical research in this area in order to understand more fully the meanings of 'struggle' and 'fight' to those who inhabit the domain.

The size of the special needs domain

Not all children with special needs attend school. Some parents choose to home-school, other children have not attained school age and some do not appear on a school roll as they are permanently excluded from school. However the government figures of school-aged children

recorded as having SEN and/or a disability, provides an indicator of the numeric size of the special needs domain. About one in five children are identified as having special needs at some point in their school career. In January 2010, of the 8,064,300 pupils on school rolls in England, 120,920 school-aged children were recorded as having SEN and/or a disability that required a statement of SEN (Ofsted, 2010, p. 79), with a further 1,470,900 having SEN and/or a disability without a statement (Ofsted, 2010, p. 79). A statement of SEN signifies children with needs such that they require "additional or different educational provision to be made for them" (DfE, 2011, p. 18)[3]. During the period 2003 and 2010, the percentage of children identified as having SEN or a disability, without a statement increased from 14% to 18.82% of the school population (Ofsted, 2010, p. 79). The proportion of school-aged children with statements of SEN has remained largely unchanged during the past decade at around 3% (DfE, 2012a).

'Special needs' or 'special educational needs'

The language of special needs can be confusing and contentious. There is a tendency for the term 'special needs' to be used as shorthand for 'special educational needs', even though the latter has a specific meaning in the contest of SEN and disability legislation, referring to children who

> …have a significantly greater difficulty in learning than the majority of children of the same age; or have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority (DFES, 2001, p. 6).

Throughout my thesis, I use the broader descriptor 'special needs' in preference to 'special educational needs', except when referring specifically to aspects of the education system, indicating that special needs are not restricted to educational settings.

Truss argues that "current conceptions of the SEN system are located exclusively or primarily within the educational system and fail to take into account the full complexity of the system (2008, p. 365), going on to discuss how families with a child with special needs do not only relate to the education system, but to the health and legal systems. I differ from Truss, suggesting that it is more appropriate in many circumstances to speak of the special needs domain rather then the SEN system, and I suggest this domain is wider than the education, health and legal systems identified by Truss, including social care and community systems.

In her examination of the language of special needs, Corbett wrote:

> One thing of which we can be certain is that the 'politically correct' language we now feel comfortable with in 1996 will appear crudely insensitive and inappropriate by the year 2010 (1996, p. 101).

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[3] A brief description of the current SEN assessment system is provided in Appendix B.

However many issues around the language of 'special needs' and 'disability' continue to be problematic and contested in 2013, as discussed in Chapter Three.

The term 'special *educational* needs' is used interchangeably with the more generic term 'special needs' in both academic literature and common parlance. Whereas 'special needs' implies a child might have support needs in school settings and/or beyond the school gate, special *education* needs refers primarily to school settings making the conflation of the two terms problematic. Some children with special needs do not have SEN, but may have other needs. This is addressed to some extent by the introduction of the term 'additional needs' in Every Child Matters (HM Treasury, 2003; Marrable, 2011), recognising that many children at some time have needs additional to those of most children. In Scotland, the term 'additional needs' has replaced 'special educational needs' (Williams et al., 2009), but SEN continues to be used in the remainder of the UK, including in the draft legislation for the reform of the SEN system (Secretary of State for Education, 2012).

The words 'special' and 'needs' are equally problematic. Although 'special' has positive connotations, such as when used in the context of a 'special gift' or a 'special occasion', in the context of disability it emphasises the relative powerlessness of disabled people (Corbett, 1996, p. 49). The charitable undertones of 'special' and 'needs' emphasise notions of dependency. Corbett suggests reclaiming the word 'special' to imply difference and a positive agency for change. Other authors suggest replacing 'needs' by 'rights' (Runswick-Cole & Hodge, 2009).

My decision to use the terms 'special needs' and 'special needs domain' is largely pragmatic. The term 'special needs' is more commonly used and understood than 'additional needs'. By referring to the special needs domain and to that part of the domain concerned with AS/HFA, I am using convenient, if problematic, shorthand.

Research questions

My central research question focuses on how and why the special needs system is experienced and viewed as adversarial, despite being established on a foundation of partnership and collaboration. In order to address this question, I identified two further questions, each with sub-questions:

- What is the structure and functionality of the systems that comprise the special needs domain?

    - What are the influences shaping the special needs domain?
    - How have these influences contributed to tension within the domain?
    - How do the various systems and subsystems within the domain interconnect?

- How does the structure and shaping of the domain and its environment contribute to the struggle/fight metaphor?
- How do the people involved with the special needs domain experience struggle and fight?
  - What areas of tension experienced by parents and practitioners originate in the systems comprising the domain?
  - What other forms of struggle and fight do parents and practitioners experience?

In returning to my central question, I draw connections between the findings emerging from the two subsidiary questions and their sub-questions.

Research approach

My theoretical framework and methodology are discussed in detail in Chapters Two and Five respectively. I use a whole *system* approach, which is not to be confused with social systems theories such as those developed by Parsons (1951) and Luhmann (King, 2009; King & Thornhill, 2005). A whole *system* approach provides a framework for exploring a problem area from a variety of perspectives, using a mixture of theoretical perspectives and techniques, in order to gain a more holistic view of the problem area than might otherwise be possible. Whole *systems* approaches have been used in governmental and other research studies in recent years, being endorsed by the UK government (HM Treasury/DfES, 2007), following a Demos report (Chapman, 2004). *Systems* ideas, based on the work of Midgley (1992) and Ulrich (2000), were used in the exploration of collaborative working in children's services undertaken by the Teaching and Learning Research Programme (TLRP) funded study, 'Learning in and for Interagency Working' (Edwards et al., 2009). This study drew attention to segmentation in the special needs domain and suggested whole *system* approaches to the domain could result in more integrated and holistic services.

As *systems* approaches have not been as widely adopted in the social sciences as in some other disciplines, Chapter Two includes a brief background to the development of *systems* thinking and the *systems* discipline. I also outline Bourdieu's *field* theory and discuss the similarities and differences between *systems* thinking and Bourdieu's conceptual framework, recognising Bourdieu's statement that his theoretical model of a *field* is not analogous to a *systems* approach such as that developed by Luhmann (Bourdieu & Wacquant, 1992, pp. 102-104). Bourdieusian concepts of capital, habitus and hysteresis are used in understanding the tensions leading to struggle and fight described in the narrative accounts of parents and practitioners, as discussed in Chapters Six, Seven and Eight. In analysing this data, I also draw on Mills' (1959) distinction between 'personal troubles' and 'public issues' and Bronfenbrenner's (1977, 1986) ecological *systems* model.

Using a *systems* approach to draw on different theoretical perspectives and traditions enables me both to view the big picture and to identify detail, to look at the *system* environment and environmental influences, and to explore interconnectivity between the parts. While the *systems* practitioner explores the structure and functionality of the domain, identifying subsystems and pressure points, Bourdieu considers the domain as a number of discrete *fields*, using the metaphor of a game to view social agents as players with different attributes, striving towards various goals, and acquiring skills and competencies on the *field* of play (Bourdieu, 1985; Bourdieu & Wacquant, 1992). In contrast, Mills takes a cross-section of the problem area, opening the way to differentiate public from personal and 'personal troubles' from 'public issues'. Bronfenbrenner, in turn, focuses on the individual and their interactions within a network of microsystems, simultaneously recognising the influences of *systems* external to the individual's personal network.

Combining *systems* approaches and sociological concepts may be considered unusual, but the use of a diverse theoretical framework is supported by Taber (2010), who argues "researchers must continually push methodological boundaries in order to address research questions that cannot be explored with traditional methods" (p. 6). Similarly, Runswick-Cole (2007a) argues that the use of a diverse theoretical framework reflects the complexity of the SEN system and Todd commended an activity systems approach as it "puts human activity into the social, political, historical and economic context in which it occurs" (2007, p. 16), stating:

> We cannot understand what kinds of partnerships between children, young people, parents and professionals are needed to develop inclusive education without taking into consideration the history of the development of relationships between families and schools (2007, p. 16).

Autism spectrum conditions

I have chosen to explore the experience of the 'struggle/fight metaphor' in the special needs domain through the experiences of those who work with or parent children and young people with diagnoses of AS/HFA for a number of reasons:

Firstly, AS/HFA is an identifiable and growing subset of special needs. The number of school-aged children with an autism spectrum condition (ASC), including those children and young people with AS/HFA, forms a substantial and increasing proportion of the school population identified as having SEN. In January 2010, 56,000, or 8.1%, of all school pupils with SEN had ASC identified as their primary SEN (Ofsted, 2010, p. 81). Pupils with an ASC and a statutory statement of SEN accounted for 18.8% of all pupils with statutory assessments of SEN in January 2010 (Ofsted, 2010, p. 81), thus forming the largest category of statemented children. The number of pupils with a primary SEN of speech, language and communication difficulties (SLC) or behavioural, emotional and social difficulties (BESD) also showed growth.

Given the contested nature of ASC diagnosis and that these figures only record primary SEN, it is possible some children with these primary SEN also have an ASC as a secondary or other special need.

Secondly, there has been a considerable increase in diagnoses of autism in recent years. Estimates vary as to the prevalence of autism, a UK study finding a prevalence of all ASCs of 116 per 10,000 (Baird et al., 2006), in contrast to the previous estimated prevalence of 60 per 10,000 across all countries (Fombonne, 2005) and earlier estimates of 5 per 10,000 (Filipek et al., 1999). This increase is generally viewed as reflecting changes in diagnostic practice (Fombonne, 2005; Russell et al., 2010; Rutter, 2005) rather than an actual increase in prevalence. Although children and young people with AS/HFA may not have the profound difficulties associated with classic 'Kanner' autism, they can be socially severely disabled.

Thirdly, children with AS/HFA form a distinct group within those with special needs, including those with other ASCs. They tend to be diagnosed later (Howlin & Asgharian, 1999) and are visually indistinguishable from their peers, but their poor social skills, combined with the behavioural difficulties associated with the condition, can place these children at greater risk of negative labelling, bullying and school exclusion than 'typically developing' children, presenting particular problems to both parents and practitioners (DfE, 2011; Humphrey & Symes, 2010; Ofsted, 2010; Reid, 2011; Ryan, 2010; Symes & Humphrey, 2011).

Fourthly, ASCs, in particular AS/HFA, are considered new disabilities together with dyslexia, dyspraxia and attention deficit hyperactivity disorder (ADHD) (Dyson, 1997, p. 155). The UK guidelines for the diagnosis of ASCs in children and young people have recently been reviewed (NICE, 2011) but the diagnosis is contested and may be subject to revision in the future following the publication of the revised Diagnostic and Statistical Manual of Mental Disorders, currently expected in May 2013.

Finally, I have personal experience of the special needs domain in relation to AS/HFA as both the parent of a young man diagnosed with Asperger's Syndrome (AS) and the facilitator of a support group for parents of children with special needs.

Kanner first proposed the use of the term 'autism' in his seminal paper (Kanner, 1943), and, though autism was recognised prior to 1980, it was then that it was first formally recognised as a medical condition, through inclusion as a pervasive developmental disorder in the third edition of the 'Diagnostic Manual of Mental Disorders' (DSM-III). Asperger first described the syndrome bearing his name in 1944, but his work did not become more widely known until the 1980s when his paper was translated into English by Uta Frith and the use of the term Asperger's Syndrome was proposed by Lorna Wing (1981). There are currently three main diagnostic categories of ASC, namely autism, Asperger's Syndrome and PDD-NOS (Pervasive Developmental Disorder - not otherwise specified). As discussed in Chapter Six, there is some

evidence that the diagnostic label given to children and young people with high functioning autism is determined more by the diagnosing consultant than whether the exact criteria of a diagnostic category have been met (Lord et al., 2012). People with autism exhibit a "triad of impairments in social reciprocity, language impairment, and reduced imagination and restricted activities" (Baird et al., 2006, p. 210). The diagnosis is contested, with some specialists suggesting autism is a socially and culturally constructed response to modern life (Timimi et al., 2011), while others suggest AS/HFA should be redefined as a different, and sometimes advantageous, way of functioning (Baron-Cohen, 2002; Molloy & Vasil, 2002).

Metaphors

Metaphors are a fundamental element of the English language (Lakoff & Johnson, 1980a, 1980b) and are used in all aspects of life. Both Bourdieu and Lewin make extensive use of metaphor in their writing, Bourdieu (1985) referring to 'field', 'game' and 'playing the game' or having a 'feel for the game' and Lewin (1951) developing a topographical model based on *field* structures and force fields. Both Bourdieu and Lewin acknowledge the influence of Cassirer as foundational in the development of their ideas, and Morgan (1980) also relates his work on the use of metaphor in organisational sciences to Cassirer's understanding of metaphor as a making the world concrete by giving it symbolic form (Cassirer, 1946, 1955 as cited in Morgan, 1980, pp. 609-610). In her essay on illness as a metaphor, Sontag (1979) discusses the use of metaphor in descriptions of chronic illness, identifying the different metaphors used to describe tuberculosis and cancer. In the autism/HFA domain, people with autism and other neuro-diverse conditions may speak of their brains being wired differently (Ortega & Choudhury, 2011), reflecting scientific findings indicating possible differences in 'autistic' brains from those of people with no signs of autism (Brun et al., 2009; Hyde et al., 2010; Samson et al., 2012; Weinstein et al., 2011). In the 1950s and 60s, Bruno Bettelheim described mothers of children on the autism spectrum as 'refrigerator mothers' (Feinstein, 2010). Todd and Jones (2003) suggest that in order not to be viewed as 'selfish', some mothers focus on the needs of their children rather than allowing their own needs to be recognised and addressed. Recently, the accolade 'warrior-hero' has been used to describe some mothers in recognition of their endeavours on behalf of their children (Silverman, 2012; Sousa, 2011), echoing Fleischmann (2005).

The phrase 'struggle/fight metaphor' is used to describe the areas of tension and struggle experienced by parents and practitioners in the special needs domain including adversarial relationships with and within the SEN system. Sometimes participants in the study used militaristic language directly, and at other times the metaphor was evident in what was described, even though metaphorical language was absent. I use a qualitative thematic approach in analysing the narrative accounts rather than discourse analysis methods; though,

when appropriate in reporting my research findings, I do draw attention to participants' use of language, especially where this is relevant to my theoretical framework.

Thesis structure

The rest of the thesis is structured as follows:

Chapter Two discusses the theoretical framework underpinning this research. I offer an overview of *systems* approaches and *systems* thinking and discuss the relationship of these ideas to Bourdieu's theory of practice and how these approaches might complement each other. I also introduce Mills' differentiation of 'public issues' and 'personal troubles' and Bronfenbrenner's family system model.

Chapters Three and Four contextualise the special needs domain. In Chapter Three, I discuss the development of the domain during the past four decades, focusing on legislation underpinning SEN provision and the socio-political influences that have shaped and influenced the domain. Chapter Four is a review of the research literature relevant to the 'struggle/fight metaphor' in the special needs domain. Both chapters close by identifying themes that assist in understanding the roots of struggle and fight in the special needs domain.

Chapter Five describes my methodological approach and the research design used in this study. I discuss the influence of *systems* thinking on the overall research design before turning to the detail of the research process. I discuss stakeholder involvement, ethical considerations, sampling, interview method and data analysis.

Chapters Six to Eight explore the experiences of struggle and fight of parents and practitioners participating in this study. I use Mills' differentiation of 'public issues' and 'personal troubles' as a framework, suggesting the 'struggle/fight metaphor' represents a continuum between personal struggles, or 'personal troubles', as experienced in both personal spaces and public places, and fight, where there is a confrontation between an individual and 'the system' due to the response to a 'public issue' being experienced as inappropriate or inadequate.

Chapter Six presents an overview of the 'everyday' experiences of struggle as discussed by participants. I locate 'personal troubles' in both personal and public spaces and consider the consequence of struggles emerging in public spaces. I address how people involved with the special needs domain experience tensions that remain struggles, as opposed to those struggles that lead to conflicts that can be described as 'fight'.

Chapter Seven considers the resources of parents and practitioners as they enter the *field* of struggle of the special needs domain and the effect on habitus of engaging in struggle,

including the use and accumulation of social and cultural capital (Bourdieu, 1977, 1985; Moore, 2008; Peillon, 1998). Reference is made to the hysteresis effect (Bourdieu, 1977) in exploring confrontations that result in disjunction. These confrontations occupy the intersection of personal and public domains and can be viewed as struggle short of fight.

Chapter Eight investigates the notion of system failure, considering situations where people perceive themselves as fighting the system. I explore the limitations of agency and power and suggest that 'public issues' continue to be 'personal troubles' for the individuals involved even when they are addressed by a public response.

Chapter Nine concludes the thesis. I discuss how I have addressed the research questions and summarise my findings before critiquing the research process, reflecting on my learning, and considering how the work described in the thesis can be disseminated and built upon.

Chapter Two

Theoretical Background

The theoretical framework underpinning my investigation of the 'struggle/fight' metaphor in the special needs domain is rooted in *systems* approaches. Such approaches emanate from the *systems* discipline, or transdiscipline (Jackson, 2000), and are based on the principle of viewing a problem area, or *system* of interest, from multiple perspectives and positions. Ideas and concepts from different traditions and disciplines are used together in gaining fresh insights into a problem area. Such a combination of theoretical and disciplinary approaches can be unfamiliar and uncomfortable. I view *systems* approaches as enabling more holistic understanding of a problem area than is possible from any single perspective. By drawing on concepts and ideas from different traditions and disciplines, an understanding of the different dimensions of tension within the special needs domain is gained, that forms a basis for understanding the interconnectivity between these different forms of tension.

In the first part of this chapter I introduce *systems* approaches, differentiating *systems* approaches from social systems theories (King, 2009; Parsons, 1951), by discussing the development of *systems* thinking and the *systems* discipline, recognising the contributions made by various disciplines. I then outline Bourdieu's *field* theory before contrasting his approach with *systems* thinking. I acknowledge Bourdieu's assertion that his *field* theory is not a *systems* theory, such as that developed by Luhmann (Bourdieu & Wacquant, 1992, pp. 102-104), but consider whether there is a greater symmetry between *field* theory and *systems* approaches when 'soft systems' are taken into account. In particular, I ponder whether '*field*' and '*system*' are interchangeable concepts. *Systems* approaches and *field* theory recognise the actions of social agents, but are agnostic regarding the 'felt' and 'lived' experiences of individual social actors. In order to provide a structure for locating individual experience of struggle and fight, I turn to Mills' differentiation of 'personal troubles' and 'public issues' (1959, p. 10) and Bronfenbrenner's[4] ecological, or family system, model (Bronfenbrenner, 1977, 1986). Finally, I outline how these different approaches and theoretical perspectives are used in modelling, analysing and interpreting my research data.

Systems thinking

Nowotny (2005) has drawn attention to an increasing interest in *systems* thinking and ideas in recent years in the social sciences, fuelled by the popularisation of chaos theories, but

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[4] Bronfenbrenner was influenced by *systems* ideas, particularly Lewin's field theory, in developing his model, but is not generally regarded as a mainstream systems theorist in the systems literature, hence I differentiate his contribution from that of the systems discipline, but recognise similarities between his approach and the nested models developed by Boulding, as discussed in the first part of this chapter.

reflecting the complexity and inter-relatedness of many facets of society requiring interdisciplinary and transdisciplinary approaches to analysis and understanding. In this section I differentiate *systems* thinking and the *systems* discipline from the social systems theories developed by (Parsons, 1951, 1961) and Luhmann (King, 2009; King & Thornhill, 2005). I identify the roots of *systems* thinking in the nineteenth century, before focusing on the development of *systems* ideas in the latter part of the twentieth century.

What is a system?

At its simplest, a '*system*' is a collection of entities or parts, organised or connected to each other, so that they work together for a purpose. This can be illustrated by considering a familiar mechanism such as a bicycle (Checkland & Poulter, 2010; The Open University, 2002b). The various parts of a bicycle do not constitute a personal transport system until they are appropriately assembled and a rider added. *Systems* commonly contain subsystems, as with the braking and steering systems of a bicycle. These subsystems may have an existence independent of the *system*, or may only have meaning within the *system* they form part of. *Systems* have boundaries, but can be affected by entities beyond the *system* in the *system's* environment, and may form part of a larger *system*. A thorn puncturing a bicycle tyre is not part of the bicycle system, but exists in its environment and influences the effectiveness of the *system*. Similarly, traffic lights are not part of the bicycle system, but part of a wider transport management system, which controls the movement of bicycles and other vehicles. *Systems* thinking involves exploring *systems* from different perspectives, sometimes focusing on detail and sometimes on the big picture (The Open University, 2002a).

Roots of systems thinking prior to 1950

The roots of *systems* thinking can be traced to Aristotle (Baldwin et al., 2010; Ramage & Shipp, 2009; von Bertalanffy, 1972) and the spiritual traditions of Hinduism, Buddhism, Taoism and Sufi-Islam as well as in many indigenous tribal spiritual traditions (Reynolds, 2011), all of which recognise a whole as comprising many parts. The *systems* discipline, as we know it today, has its roots in the nineteenth century and the growth of engineering sciences and development of mechanised systems alongside a growing awareness of organic systems in the biological and medical sciences.

The growing interest in *systems* and connectivity influenced the embryonic social sciences, including some of the 'founding fathers' of sociology. Pareto, Durkheim and Spencer included *systems* ideas in their contrasting theories exploring the construction and functioning of society (Jackson, 2000). Pareto, an Italian economist and sociologist, adopted a mechanistic view of society as "a system in equilibrium which, despite surface changes, seeks to return to its original state" (Jackson, 2000, p. 54). Spencer, an English philosopher, sociologist and biologist, and Durkheim, a French sociologist, adopted organic analogies, viewing society as

"a system made up of interconnected parts functioning to maintain the whole…[and]…capable of evolving in response to environmental and other changes" (Jackson, 2000, p. 54). Strong emphasis was placed on the orderliness of society, in which all the components of the *system* had their place and were necessary in order for other components to operate efficiently, reflecting the thinking and theology of the time, as typified in the now deprecated verse of the hymn, 'All things bright and beautiful':

> The rich man in his castle,
> The poor man at his gate,
> He made them, high or lowly,
> And order'd their estate (Alexander, 1848).

The development of systems thinking following the Second World War

Systems thinking in the twentieth century can be thought of as having developed in three waves (Midgley, 2000). The first wave used modelling and simulation techniques to understand and bring about change in problem situations. The second wave developed during the 1970s and 1980s and moved from mechanistic modelling to taking into account 'soft systems', that is, the actions and intentions of human beings, and their influence on the *systems* they form part of. The third wave introduced consideration of power into *systems* thinking and drew on ideas from chaos and complexity theories.

First wave of *systems* thinking – modelling and simulation

The Second World War created a renewed interest in *systems* thinking and multidisciplinary approaches to problem solving and development work emanating from the burgeoning defence industry, which brought together engineers and scientists from a wide range of backgrounds (Jackson, 2009). In the early post-war period, theorists from different disciplines came together to develop a General System Theory (Boulding, 1956; von Bertalanffy, 1950), drawing on ideas from the engineering and life sciences. Although there is no evidence that Parsons, an American sociologist, was involved in these endeavours, it is possible he was influenced by these ideas in his quest to develop an all-embracing theory of society (Parsons, 1951). Parsons' ideas were influential in the development of management sciences and organisational theory (Ramage & Shipp, 2009), both of which were a focus of attention in the second wave of *systems* thinking, but tend to be regarded as peripheral to the development of the *systems* transdiscipline.

During the early post-war period *systems* theorists also used organic models in developing ideas about connectivity within and between *systems*. Boulding (1956) was prominent in contributing to the development of a General System Theory through the development of a hierarchical model that demonstrated the relationship between simple, lower order, organic systems and more complex, biological systems, paving the way for more complex *systems*

models that incorporated nested and interdependent subsystems and the sharing of attributes between different *system* entities. Later extensions of these ideas recognised that the efficient functioning of subsystems did not imply the whole *system* was working optimally (White, 2000), and that the interaction between the *system* and its environment was fundamental to its performance (Fisher, 1993 cited in White, 2000).

The second wave of *systems* thinking – the human factor

The second wave of *systems* thinking is the most interesting in the context of this thesis, as it marks a move from engineering, mechanistic and organic systems to *systems* incorporating soft complexity in the form of human influences. During the 1970s and 1980s, it was increasingly recognised that many *systems* concepts were not immediately applicable to complex human-based systems. Peter Checkland (2000) and others developed soft *systems* approaches, which incorporated soft *systems*, or human interrelationships, and their effects on the functioning of *systems*. This signalled a move to holistic, emancipatory, whole *system* approaches, which were promoted as being more effective in achieving change than the earlier reductionist, problem-solving methodologies (Checkland, 1999, 2000). Soft systems methodologies explicitly include stakeholder perspectives, sometimes using force field concepts, based on the ideas of Kurt Lewin (Burnes & Cooke, 2012; Lewin, 1951; Melin, 1987), and sometimes using various diagramming techniques, including rich pictures, and explicitly focus not only on the functionality of the *system* (hard systems), but also on the interrelationships of people (soft systems). Checkland's ideas and methods have been adopted extensively in UK health service planning and have been advocated for use in the development of public policy more generally (Chapman, 2004).

Bronfenbrenner's (1977, 1986) development of a family system model marked another development in more human centred *systems* thinking. This model is discussed in more detail later in this chapter, but uses biological and organic systems ideas, including nested *systems*, and draws also on Lewin's topographical model (1951). Although mentioned here, Bronfenbrenner is not generally regarded as a *systems* theorist within the *systems* discipline.

A further development in *systems* thinking recognised that *systems* were not only functional, but had meaning. Tensions occur in *systems* when the objective of the *system* differs from that of its subsystems (Jackson & Keys, 1984). Similarly, Ackoff suggests the ostensible function of a *system* may not be the same as its actual function:

> The health care system of the United States is not a health care system; it is a sickness and disability care system…Since the revenue generated by the current system derives from care of the sick and disabled the worst thing that can happen would be universal health (1999, p. 427).

In exploring any *system*, it is important to ask not only what its purpose is understood to be, but also what purpose it actually fulfils.

The third wave of *systems* thinking – chaos, complexity and communications

More recent developments in *systems* thinking incorporate ideas from chaos and complexity theories (Jackson, 2000; Mingers & White, 2010; Nowotny, 2005; Tsoukas, 1998), and work in the area of communications. From both a *systems* and social science perspective, Luhmann is an important contributor to communications theories and the integration of biological thinking into *systems* approaches. Luhmann's early work was influenced by Parsons, but more important influences were Habermas (Habermas & Luhmann, 1971, as cited in Ramage & Shipp, 2009) and work in the biological sciences focusing on autopoiesis, or self-maintaining *systems* (Luhmann, 1992, 1993).

The influence of *systems* thinking on my research

As in other disciplines, there are many *systems* methodologies and approaches, each with associated methods and techniques. As with any discipline, there are purists, but Checkland (2000) emphasises the permissive nature of the *systems* discipline, whereby *systems* practitioners adopt eclectic approaches, drawing on ideas and techniques from different *systems* methodologies and other disciplines within a single investigation, according to the needs and purpose of that investigation. This perspective is endorsed by the Systems Practice Group at The Open University, which developed a generic *systems* approach (Figure 1), referred to as the SUDA model that is based on the Kolb learning cycle (Kolb, 1984). This model is described in Chapter Five, where I explain how I have used it to provide a framework for this research.
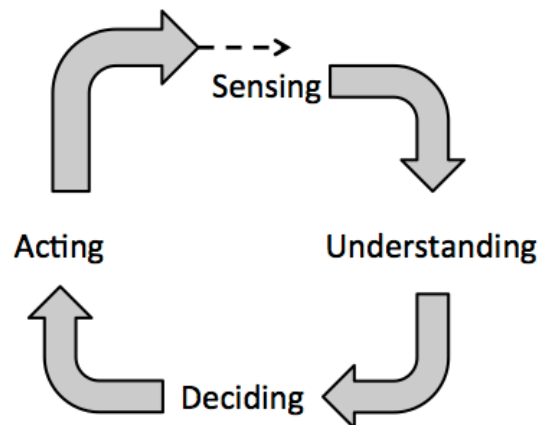
Figure 1 Four phase cycle of enquiry ©The Open University (The Open University, 2003, p. 5)

Bourdieu's Theory of Practice

Bourdieu's theory of practice was developed initially from fieldwork undertaken in Kabylia in Algeria, following the Algerian War, in the 1950s and early 1960s. Bourdieu was initially present in Algeria on military service and later as a civil servant, involved in the reconstruction of the country following the conflict. His theory of practice originated from his fieldwork observations, influenced by his previous study of philosophy (Grenfell, 2004, 2008). In his translator's foreword to Bourdieu's 'Outline of a Theory of Practice', Nice refers to the eclecticism evident in Bourdieu's work, saying this is justified "in the fact that all the resources of a tradition which from the beginning has made practice the negative obverse of theory are needed in order to think the unthinkable" (Nice in Bourdieu, 1977, p. viii).

Fundamental to Bourdieu's theory of practice is his conception of the social world as consisting of *fields* of struggle populated by social agents (Bourdieu, 1985; Bourdieu & Wacquant, 1992). Bourdieu uses three different analogies in explicating his understanding and use of 'field'. These analogies imply different attributes that Bourdieu attaches to the concept of a social *field*. The analogies are a force field, both as found in science fiction and as found in the physical sciences, and a field of play (Thomson, 2008). A force field in science fiction is a bounded area, which it is possible to depart from, but impossible to enter from outside. A force field, such as a magnetic field in the physical sciences, shows little evidence of a boundary, but forces diminish the further one moves from the source of the force field. A field of play is a contained space, or arena, but actions within it are in accordance with the rules of the game (Bourdieu, 1990, p. 67). Bourdieu does not recognise connections between *fields*, but does allow social agents to occupy more than one *field*. *Fields* are shaped by internal struggle and by the influence of changes in other *fields*, in particular the *field* of power, which is a container for all other *fields*.

Bourdieu also introduces two further interrelated concepts, habitus and capital. Habitus refers to "systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures" (Bourdieu, 1977, p. 72), or, in more accessible language, an individual's predispositions, or embodied inclinations, which result from all the various influences that person has absorbed and responded to (Ashall, 2004). Habitus is not static, but a product of early experiences in the home, reinforced and modified by experience, in particular learning (Hodkinson et al., 2007). Habitus "focuses on our ways of acting, feeling, thinking and being. It captures how we carry within us our history, how we bring this history into our present circumstances, and how we then make choices to act in certain ways and not others" (Maton, 2008, p. 52). Whereas Bourdieu views habitus as fluid, past choices and experiences shaping the habitus and influencing future choices (Bourdieu & Wacquant, 1992, p. 133), others have suggested the concept carries a sense of delimiting the options available to an individual (Noble & Watkins, 2003), leading some to consider Bourdieu deterministic.

However Bourdieu counters this in his insistence that "the practices produced by the habitus…are perceived as one strategy among other possible strategies" (Bourdieu, 1977, pp. 72-73), showing that the range of past experiences of a social agent equips that agent with a repertoire of alternative actions when confronted with further experiences. Implicit in Bourdieu's description of habitus is choice, flexibility and dynamism.

Capital describes the resources possessed by social agents. Bourdieu differentiates economic, cultural, social and symbolic forms of capital, all of which can be invested or exchanged to create additional capital (Bourdieu, 1977, 1985; Moore, 2008; Peillon, 1998). Economic capital refers to financial and realisable assets. Cultural capital represents learning and knowledge and refers to the possession of knowledge, including both accredited and informal learning. Symbolic capital is conceptualised as a form of credit that does not exist in economic form, but opens up possibilities of investment and exchange, in that assumptions are made about the wealth of a person based upon their name, family background or lifestyle, giving that person access to places or resources they might not otherwise access. Such symbolic capital may be a form of "bluff" (Bourdieu, 1990, p. 120), not representative of the actual economic status of the social agent. Social capital is defined as the "effective possession of kinship (or other) relations, capable of being mobilised or at least manifested" (Bourdieu, 1990, p. 35). For Bourdieu all forms of capital can be used to provide access to other forms of capital through investment and exchange.

The concept of social capital has been extended by Coleman (1988) and Putnam (1995, 2001), Coleman linking the notion of social capital to concepts of strong and weak ties (Field, 2003; Weick, 1976) and Putnam relating the concept to the community and the nation by introducing the notion of working together for the common good (1995, 2001). Putnam suggests that not only those involved in the creation of social capital benefit from their efforts, but also the wider community. This can be seen, for example, in the actions of disability activists who campaign for improved physical access and social inclusion, and whose actions benefit both other disabled people and others for whom physical access is important (Arai, 2006, p. 334). There is a growing consensus that "social capital stands for the ability of actors to secure benefits by virtue of membership in social networks or other social structures" (Portes, 1998, p. 6). These broader understandings of social capital are used in this thesis.

Bourdieu does not view *field*, habitus and capital as distinct from each other, but as intertwined and exerting influences on each other:

> Practice results from relations between one's dispositions (habitus) and one's position in a field (capital), within the current state of play of that social arena (field) (2008, p. 51).

He is concerned with what happens in practice. Expertise is developed through practice on the field of play. Social agents learn through engagement with other social agents (Noble & Watkins, 2003, p. 528). There is a congruity between *field* and habitus, where social agents know and understand the game. However circumstances arise when this relationship is disrupted, perhaps as a result of changes in the *field*, stemming from the influences of change in other *fields*, that have not yet been assimilated by the social agents, or when an individual enters a new *field*. Bourdieu labels such disruption between *field* and habitus 'hysteresis', referring to the 'hysteresis effect', as it is

> …necessarily implied in the logic of the constitution of habitus, practices are always liable to incur negative sanctions when the environment with which they are actually confronted is too distant from that to which they are objectively fitted (Bourdieu, 1977, p. 78).

In more accessible language, disruption between *field* and habitus can lead to a sense of confusion and disjunction, where the social agent has a sense of no longer knowing the rules of the game. This is overcome by changes in the *field* and reshaping of the habitus, bringing both back into a more harmonious relationship.

Field theory and *systems* thinking

In 1988, Bourdieu was asked what the difference was between a *field* and a *system* such as that theorised by Luhmann (Bourdieu & Wacquant, 1992). He acknowledged surface similarities between *field* theory and *systems* theory, but argued they were not the same as "the notion of a field excludes functionalism and organicism" and "a field does not have parts, components" (Bourdieu & Wacquant, 1992, pp. 102-104). As discussed earlier in this chapter, Luhmann's ideas were developed largely during the first and third waves of the development of *systems* thinking, and though his communications theory is regarded as valuable, Luhmann receives few mentions in *systems* texts. I would suggest that Bourdieu was quite right in choosing to disassociate his thinking from that of Luhmann, but that other *systems* ideas, in particular those in the second wave of the development of *systems* thinking have far more in common with Bourdieu's ideas. The *systems* ideas referred to by Bourdieu appear to relate to the first wave of *systems* thinking, which were largely mechanistic and focused on process and product, rather than to soft *systems* ideas which emphasise the role of human agents, struggle and overcoming obstacles. As commented earlier, both Bourdieu and Lewin developed their *field* theories having been influenced by the work of Cassirer. Bronfenbrenner, whose ideas are outlined later in this chapter, acknowledged that his models were based on conceptual ideas developed by Lewin. Although Bourdieu's *field* theory may not be a *systems* approach, it shares a common heritage with some approaches using *systems* ideas.

Fields and *systems* are conceived as constructed and bounded social spaces, which may not have a physical world equivalent. Bourdieu describes a *field* as an "arbitrary social construct" (1990, p. 67). Both *systems* and *fields* operate according to rules, which in the case of a *field* are a product of the habitus of the social agents within the *field* in interaction with the *field* and the influences shaping the *field*. Similarly, the rules governing a *system* include both the formal rules imposed on the *system* by its designer and informal rules reflecting the behaviour of actors within the *system*. In both cases, those within the *system* have inculcated and know the rules.

Fields and *systems* can be conceptualised as containers, a *field* containing interacting social agents engaged in struggle and a *system* comprising a combination of mechanistic elements and social actors in interaction with each other. While Bourdieu focuses on struggle for power and position within the *field*, *systems* theorists focus on the functioning of the *system* and factors that restrict its efficiency. Bourdieu considers *fields* as not interconnected, but subject to change resulting from internal struggle and the shaping caused by the influence of change in other *fields*, such changes reflecting the dynamic nature of *fields* and *field* boundaries. *Systems* practitioners lay more stress on the effect of external influences, while Bourdieu focuses on the internal dynamics of the *field* and "the relations of force between the different kinds of capital or, more precisely, between the agents who possess a sufficient amount of one of the different kinds of capital to be in a position to dominate the corresponding field" (Bourdieu, 1998, p. 34).

Boundaries are of particular interest to both Bourdieu and *systems* thinkers. Bourdieu views the *field* boundary as a site of struggle (Thomson, 2008, p. 71) while *systems* theorists regard *system* boundaries as socially constructed, malleable, and "likely to be complex, unstable and negotiable" (Edwards et al., 2009, p. 37). Whereas *field* theory conceptualises *fields* as separate from each other, *systems* practitioners view a *system* as comprising interconnected subsystems, and label the intersections of subsystems as 'boundary zones' (Konkola et al., 2007). These intersections may be experienced as neutral spaces, or as places of dissonance or struggle (Daniels et al., 2010) where changes occur to the meaning social agents give to others (Edwards et al., 2009, p. 39). Elsass and Veiga (1994) refer to these individual changes as acculturation, further suggesting that not only do changes occur at an individual level, but that as autonomous cultures change as a result of contact with each other, new *systems* are established, combining the attributes of the previous cultures. Bourdieu similarly identifies the *field* as the place where "agents confront each other, with differentiated means and ends according to their position in the structure of the field of forces, thus contributing to conserving or transforming its structure" (1998, p. 32).

Bourdieu's *field* theory is premised upon power struggles and exchange of different forms of capital. Social agents are positioned in the *field* according to their habitus and capital, both of

which are influenced by struggle and influence the outcome of struggle. *Systems* practitioners consider the influence of social agents and subsystems on decision making and change, and recognise the relative power and influence of different stakeholders (Ajimal, 1985; Elsass & Veiga, 1994).

Systems approaches and *field* theory both aid the understanding of the structure of groups, organisations and institutions and how they relate to each other. The different emphases present in the two approaches permit a problematic area of human interaction to be viewed from complementary perspectives. However, neither *systems* approaches nor *field* theory focus on the experience of individuals, both considering the 'big picture' rather than detail, though *systems* approaches do permit a range of perspectives, including homing in on specific aspects of the *system* in creating a holistic understanding of an enterprise. In order to explore the nature of the 'struggle/fight metaphor' in the special needs domain, it is not only necessary to understand the structure, shaping and dynamics of the domain, but also to consider the detail of that struggle and fight in terms of what it means to the social agents occupying the domain. I will return to these individual aspects of struggle in a later section of this chapter, but first I describe how *systems* approaches and *field* theory have been used in areas relevant to the focus of this thesis.

Systems approaches and *field* theory in practice

Systems approaches and Bourdieusian concepts have been used in a wide range of research and other studies in different environments and situations, but do not appear to have been used together by other researchers. In this section, I summarise some of the uses of these concepts in health, education and social care contexts and policy development.

Altschul (1978), an early adopter of *systems* approaches, used *systems* mapping to inform practice in psychiatric settings. She recognised the determination of the purpose and boundary of the *system* affects the placement of entities within the *system*, or its environment. A *system* map, drawn to focus on the nursing process, positions the nurse within the *system* boundary, but if the *system* map is drawn to focus on the patient's lifeworld,[5] the nurse is placed in the *system* environment. In a more recent use of *systems* approaches, Clancy et al. (2008) used computer modelling and simulation to support decision making in nursing practice. Thirty years apart, these examples not only illustrate different approaches to the use of *systems* concepts, but also are illustrative of the increasing

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[5] Altschul refers here to the everyday world of the patient. The concept of lifeworld was developed by Husserl to mean "the whole sphere of everyday experiences, orientations, and actions through which individuals pursue their interests and affairs by manipulating objects, dealing with people, conceiving plans, and carrying them out" (Wagner writing in Schutz, 1970, pp. 14-15) and further developed by Schutz (1970). Mishler uses the concept to explore doctor/patient relationships in medical interviews (Clark & Mishler, 1992; Mishler, 1984). In Germany, it was used to develop a framework for social work and social care (Grunwald & Thiersch, 2009). Habermas gives an alternative meaning to the concept, relating it to a subjective internal viewpoint.

complexity of people-centred services such as those found in health, education and social care.

Systems approaches, especially those incorporating soft systems methods, have been used extensively in the NHS and public health sectors (Bielecki & Stocki, 2010; Diez Roux, 2011; Fahey et al., 2004; Jacobs, 2004; Kalim et al., 2006; Rose & Haynes, 1999). Naaldenberg, Vaandrager et al. suggest that as *systems* become

> …more complex due to more parts, actors, interactions and communication, the origin of problems gets harder to identify…[and]…problems are often ill defined and 'fuzzy' in nature…a soft systems approach moves away from working with the idea of an obvious problem…[and]…uses the idea of a situation that…could be seen as problematical and needs to be improved (2009, p. 40).

Whereas the main focus of *systems* approaches is the purpose, or functionality of the *system*, and its structure, Bourdieu's theory of practice, and, in particular, the concept of 'field' emphasises power dynamics in ways not always evident in *systems* approaches (Emirbayer & Johnson, 2008, p. 6). Although Bourdieu advocates a structured methodological approach (Bourdieu & Wacquant, 1992, pp. 104-107), many studies use and develop his concepts rather than adopting his methodological approach. Garrett (2007) argues for the use of Bourdieusian concepts in the development of social work theory and practice and Peillon (1998) offers an application of *field* theory to understanding the sociology of welfare. There is much evidence of combining different approaches when considering the concept of social capital, including the use of mathematical modelling techniques by Schiff (1992) and Song (2012) in exploring the effect of gender and parenthood on the possession of social capital. Gazeley (2012) and Vincent (2001) use the Bourdieusian concepts of capital and habitus in exploring the relationship between parents and practitioners in school settings.

From structure to experience

As observed above, *systems* approaches and *field* theory both acknowledge individual social agents, *field* theory focusing on the *field* of struggle and struggle between social agents. Although Bourdieusian concepts such as habitus and social capital apply to individuals, Bourdieu does not offer a model for understanding the variety of human experiences within a single domain, though he does discuss individual experiences (Grenfell, 2004). Neither Mills, a sociologist, nor Bronfenbrenner, a psychologist, would be considered part of the mainstream of *systems* thinking and the *systems* discipline, but both use *systems* ideas in their work. In introducing his concept of "the sociological imagination", Mills refers to the "linkages among a great variety of milieux" and the interconnectivity of institutions (1959, p. 10). Bronfenbrenner (1977, 86) was influenced by Lewin's field theory (1951) in his development

of an ecological systems model using ideas also reminiscent of Boulding's (1956) hierarchy of complexity and nested models.

Mills differentiates 'personal troubles' and 'public issues' (1959, pp. 8-10), using examples of unemployment, war and divorce to elucidate that in each instance these were 'public issues' requiring public responses, but for the individuals involved, they were also 'personal troubles', needing to be addressed at a personal level. If one person is unemployed, it is a 'personal trouble' but if many people are unemployed, it becomes a 'public issue'. Similarly, special needs can be understood as a 'public issue', addressed through the statutory provisions made by education, health and social services in the context of the special needs domain, but also as a 'personal trouble', experienced within the family and home environment. However, 'personal troubles' may not be confined to personal spaces but are lived out in public places. In Chapters Six and Eight, I use Mills's differentiation to frame the 'struggle/fight metaphor' as experienced by the parents and practitioners participating in this research.

Bronfenbrenner is a clinical psychologist who developed what is variously referred to as an ecological systems model or a family system model (1977, 1986). The model was developed initially as a tool for viewing aspects of child development in multiple, interconnected contexts, but is used more broadly, as in Leonard's (2011) study of the changing relationship between an 'underperforming school' and the community where it is located. Bronfenbrenner notes the influence of Lewin on his work, saying his model provides "psychological and sociological substance" to Lewin's topological territories (1977, p. 515). Bourdieu and Lewin were both influenced by Cassirer and this common heritage may explain apparent similarities between some of Bourdieu's ideas and aspects of Bronfenbrenner's model, even though Bourdieu, Lewin and Bronfenbrenner aligning themselves with different traditions and disciplines. I return to this observation in Chapter Seven.

Bronfenbrenner's model consists of a microsystem, a mesosystem, which is a network of microsystems, an exosystem and a macrosystem. The microsystem is

> …the complex of relations between the developing person and the environment in an immediate setting containing that person… (Bronfenbrenner, 1977, p. 514),

which for a child consists initially of the family unit, but later broadens to include school, friendship and leisure circles and place of work. Swick and Williams refer to "the child's most immediate environment…a reference point of the world" (Swick & Williams, 2006, p. 372), which is reminiscent of Bourdieusian notion that the habitus is formed initially within the context of home and family (Bourdieu, 1990, pp. 58-68).

The mesosystem

> …comprises the interrelations among major settings containing the developing person at a particular point in his or her life…[and for a child]…typically encompasses family, school and peer group…[and]…might also include church, camp, or workplace… (Bronfenbrenner, 1977, p. 515).

It may be viewed as a *system* of microsystems, or as various aspects of the community to which the child belongs which are "proximally closer to the child" (Newbury, 2011, p. 90). Whereas the microsystem is the primary *system* for the developing individual, the mesosystem represents the next set of connections developed by the individual, and can be conceptualised as the initial social network, or the space where an individual accumulates social capital.

The exosystem includes social structures

> …that do not themselves contain the developing person but impinge upon or encompass the immediate settings in which that person is found… (Bronfenbrenner, 1977, p. 515).

It might be better understood as those "contexts we experience vicariously yet have a direct impact on us" (Swick & Williams, 2006, p. 372). In the context of special needs domain, this might include, for example, the local authority panel responsible for determining school placements of children with SEN.

The macrosystem represents "larger systems of cultural beliefs, societal values, political trends" (Swick & Williams, 2006, p. 372), including legal frameworks and governmental policies (Newbury, 2011). Bronfenbrenner echoes Bourdieu's concept of the *field* of power

> …the overarching, institutional patterns of the culture or subculture, such as the economic, social, educational, legal and political systems, of which micro-, meso-, and exo-systems are the concrete manifestations… (1977, p. 515).

The chronosystem adds a further dimension to Bronfenbrenner's model, representing the changing influences on an individual during their life course, and changes in these influences as the *systems* are subjected to change and shaping (Bronfenbrenner, 1986). Swick and Williams (2006) observe events influencing parental lifestyle in the past may constrain current lifestyle behaviours, an idea redolent of the development of habitus. Changes in any *system* influence other *systems* within the whole *system*, whether or not there is an explicit connection between those *systems* (Newbury, 2011), a notion similar to Bourdieu's observation that *fields* are shaped as a result of internal struggle and changes in other *fields* within the *field* of power.

Concluding reflections

In this chapter, I have discussed the four frameworks that I use to frame my research and to understand and interpret the data emerging from my research study, namely Bourdieu's *field* theory, *systems* thinking, Mills' differentiation of 'personal troubles' and 'public issues' and Bronfenbrenner's ecological, or family systems model. Each provides a different perspective on the problem area and together they provide a holistic approach to understanding the multidimensional nature of the 'struggle/fight metaphor'. *Systems* approaches provide a framework for viewing data in a multi-faceted way, identifying detail, exploring the domain and environmental influences, and discovering interconnectivity between the parts using a variety of different theoretical lenses. Bourdieu provides a way of looking at the *fields* that comprise the domain in the context of a game with players with different attributes, striving towards various goals, and acquiring skills and competencies during the game. Mills takes a slice through the whole identifying both the macro – 'public issue' - and micro – 'personal trouble' – aspects of the problem area. Whereas the individual can be obscured in big picture approaches, Bronfenbrenner turns the spotlight on the individual and their interactions with different networks and spheres of activity. As explored further in Chapter Seven, his model can be viewed as complementary to Bourdieusian concepts of habitus and capital.

Chapter Three

Contextualising the Special Needs Domain: public responses to a "public issue"

Children and young people with special needs represent a 'public issue' that is responded to through legislation providing assessment, publicly funded support structures and other resources. This chapter focuses on the 'systems' and structures that have been developed within the special needs domain that identify and support children with special needs and their families. These structures are not specific to children and young people with AS/HFA, but are the structures that those working with and parenting children and young people with AS/HFA work within and from which they seek support. Firstly, I present an overview of the domain, using a visual model developed in the early stages of my research process. Next, I consider the development of the SEN system over the last forty years, recognising it as the principle provider and coordinator of services for children and young people with special needs. I then turn to factors that have influenced the development of special needs provision, including changing emphases in public policy and changing attitudes to and perceptions of disability. In my concluding reflections, I turn to considering the sources of tension emanating from the structure of the special needs domain and the influences on it that contribute to it being described as adversarial. These factors will be returned to in Chapters Six to Eight as I explore the experiences of the participants in the empirical study that formed part of this research.

The structure of the special needs domain

The special needs domain, as I am defining it, consists of a range of statutory bodies, voluntary organisations, private providers and community groups that include in their remit the provision of support and services to children and young people with special needs. Some of these are concerned only with special needs, while others, such as education and health services, have a wider remit. Similarly, some have a primary role in supporting children and young people with AS/HFA while others may only be involved with these children and their families under exceptional circumstances. The diagram in Figure 2, which was developed during the second stage of this research as described in Chapter 5, shows the major subdomains that comprise the special needs domain together with constraints and influences on the domain. As with any *systems* diagram, this is a visual representation drawn from a specific perspective. It could be argued that the welfare benefits system should be included and it is equally arguable that social care has too high a profile in the context of research

focusing on AS/HFA, as relatively few children and young people with ASCs qualify for support from children's services (Goodley & Runswick-Cole, 2011).
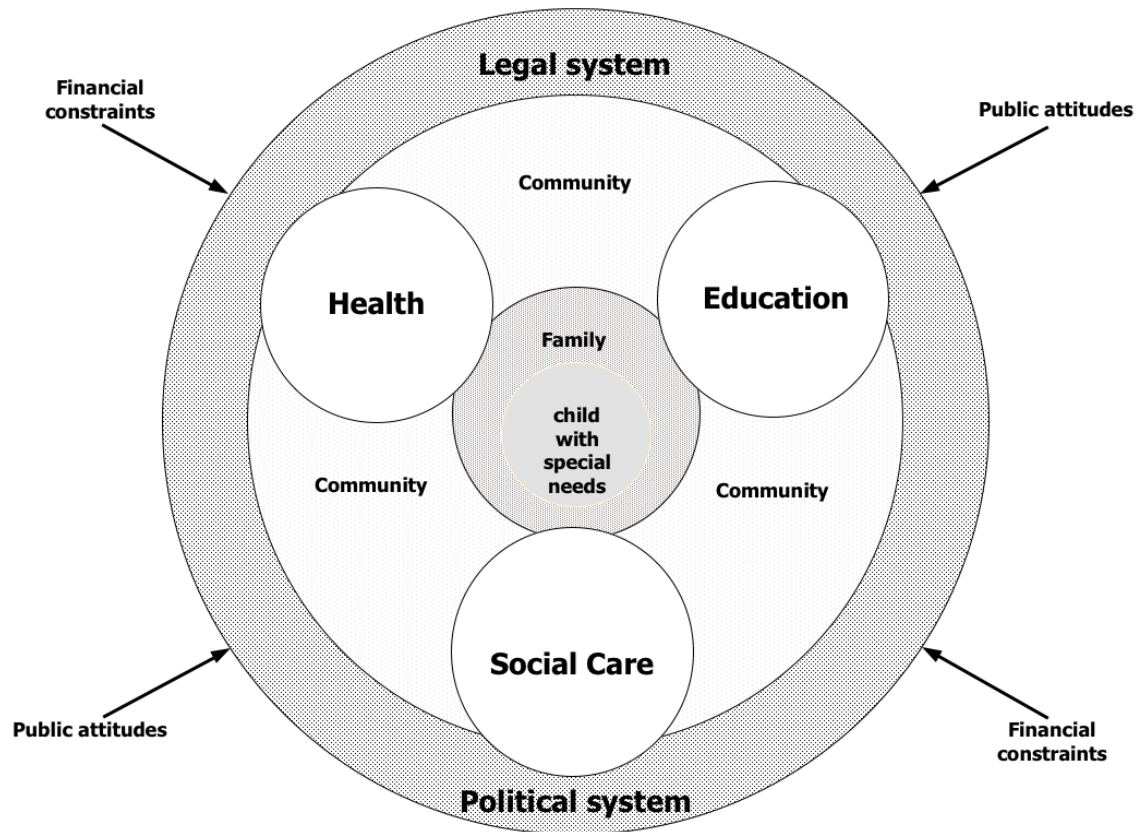
Figure 2 Structural overview of the special needs domain showing the
principal elements comprising the domain and constraints on the domain

In considering the public response to special needs, the highest profile subdomains are education and health. Education is responsible for the assessment of SEN and the health services for the diagnosis of conditions that are considered disabilities and can result in a person being categorised as having special needs. As shown in Figure 3, the diagnostic and SEN assessment processes are separate from each other, but inform each other. Jacobs (2011) suggests that many parents believe a medical diagnosis is necessary in order to access in-school support and assessment of SEN. However, the SEN Code of Practice suggests this is not the case, and that there is no direct connection between diagnosis and in-school support (DFES, 2001), though medical advice is requested as part of the process of gathering and collating information during the formal process of a statutory assessment of SEN. The SEN Green Paper (DfE, 2011) recommends changes in the assessment of special needs, including the replacement of the statement of SEN with an education, health and social care plan (EHCP). This proposal is embedded in the draft legislation (Secretary of State

for Education, 2012), which, if enacted, could lead to a closer relationship between the assessment processes. At the time of writing, it is understood some aspects of these proposals present problems that are as yet unresolved, in particular the funding arrangements and whether the provision of health inputs defined in the EHCP will be a statutory requirement, in the same way as is the case with educational provision defined in a statement of SEN.
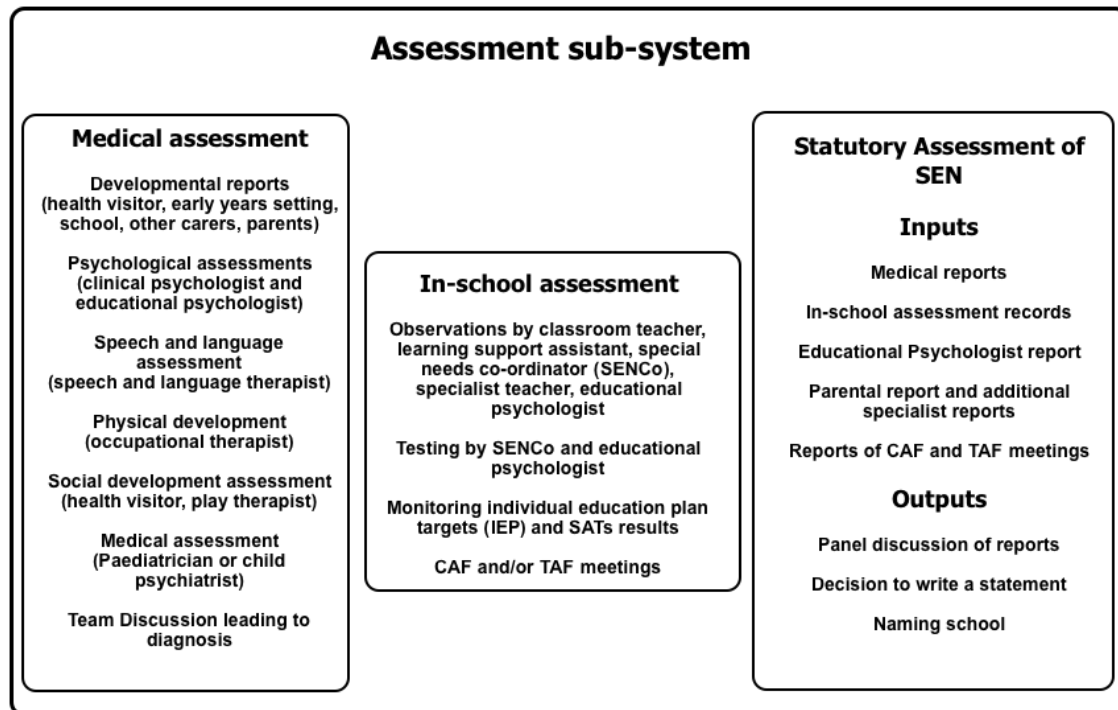
Figure 3 Special needs assessment - medical and educational

I now turn to the development of the formal SEN system over the past four decades. The SEN system, though education focused, is viewed as the principle provider and coordinator for services to children and young people with special needs. It is central to the public response to special needs as a 'public issue' and relevant to this investigation as many children with AS/HFA are on school SEN registers.

The development of the legal framework for SEN provision

The SEN system, as it currently exists, has its roots in the legislation following the report of the Committee of Inquiry into the Education of Handicapped Children and Young People, better known as the Warnock Report (DES, 1978). The Warnock Committee was established in 1975, following the transfer of responsibility for the education of all school-aged children to local authorities under the Education (Handicapped Children) Act (HM Government, 1970b). Prior to this legislation some children were deemed ineducable and had been the responsibility of the health service, receiving little or no formal education and attending junior

training centres, or were accommodated in large institutions. Other children, who were regarded as slow learners, attended special schools, while children with physical and sensory impairments might attend specialist residential schools (Borsay, 2011; Tomlinson, 2012). The 1976 Education Act (HM Government, 1976) introduced the possibility of mainstream schooling for children with special needs (Jackson, 2005), paving the way for the reforms recommended by the Warnock Committee. These included the introduction of the term 'Special Educational Needs' to replace the multiple categories of impairment used to differentiate children with different special needs, the implementation of statutory assessment and statement of SEN, collaborative working between education authorities and others supporting children and families with SEN and the appointment of key workers.

These recommendations were enacted in the 1981 Education Act (HM Government, 1981) with the exception of the appointment of key workers. The reforms were intended to develop integrative approaches to education "based on common educational goals for all children regardless of their abilities or disabilities" (House of Commons Education and Skills Committee, 2006, p. 11), but the legislative changes were not accompanied by additional funding and came at a time when cuts in education expenditure were being imposed (Norwich, 2010). Although there was no formal policy to close special schools, there was an implicit understanding special schools would be closed in order to release funding to better resource mainstream schools. Arguments over special school closures and funding special needs provision in mainstream schools continue into the present century (House of Commons Education and Skills Committee, 2006) and remain unresolved.

Since the enactment of the 1981 Education Act (HM Government, 1981) there have been a number of amendments to SEN legislation. These include the introduction of a tribunal system enabling parents to appeal against local authority decisions in relation to school placement and statutory assessments of SEN, the publication of the SEN Code of Practice (DFES, 2001) and the incorporation of the provisions of the 1995 Disability Discrimination Act (HM Government, 1995) in the 2001 SEN and Disability Act (HM Government, 2001).

The SEN reforms were criticised from their inception (Lewis & Vulliamy, 1980). Increasingly the SEN system has been viewed as unfit for purpose. In 1997, the New Labour government published a consultation document (DfEE, 1997) leading to discussion about the merits of inclusive education, a revised SEN Code of Practice (DFES, 2001) and a strategy document (DfES, 2004), but no formal changes to the system. In 2005, Baroness Warnock, chair of the Committee bearing her name, published a pamphlet advocating a review of SEN legislation, identifying failings in the Warnock Report recommendations (Warnock, 2010). A House of Commons Select Committee discussed the debates around SEN (House of Commons Education and Skills Committee, 2006) and the following years saw a number of reviews and inquiries focusing on different aspects of special needs, including a review of services for

children and young people with speech and language difficulties (Bercow Report, 2008), an inquiry into special educational needs and parental confidence (Lamb Inquiry, 2009), a review of teacher supply for pupils with severe, profound and multiple learning difficulties (Salt, 2010) and an Ofsted review of special educational needs and disability (Ofsted, 2010). In March 2011, the coalition government published a consultation document reviewing SEN provision and legislation (DfE, 2011), followed by a report of the consultation (DfE, 2012b) and draft legislation (Secretary of State for Education, 2012). Legislation is anticipated before the 2015 General Election.

The public policy background

Changes in special needs provision have not taken place in a vacuum, but against a background of changes in other areas of public policy, bringing about changes in other areas of public provision for people with special needs and disabilities. The 1970 Education Act was enacted two years after the publication of the Seebohm Report (HMSO, 1968), recommending major changes in the provision of public health, social care, welfare and children's services. The Local Authority Social Services Act (HM Government, 1970c) did not create the unified health and welfare departments recommended by Seebohm. Instead local education authorities retained control of education welfare services and public health responsibilities were transferred to the NHS (Dickens, 2011), but generic social services departments were established. The separation of education welfare from other social and welfare services had implications for the development of interagency collaboration in developing special needs provision. 1970 also saw major legislation giving people with disabilities the right of equal access to recreational and educational facilities and making provision for local authorities to enable disabled people to continue to live in their own homes, by making physical adaptations to buildings and supplying aids and practical assistance. The Chronically Sick and Disabled Persons Act (HM Government, 1970a) benefited not only disabled adults, but also made it possible for disabled children and young people to live at home rather than in institutions.

Underlying the changes in public policy legislation during the late 1960s and early 1970s was a growing emphasis on collaboration and interagency working. The roots of collaborative working are evident in the Plowden Report (1967), reviewing educational provision, the Seebohm Report (HMSO, 1968) and the Warnock Report (DES, 1978), but during the 1980s these trends were replaced by an increasing emphasis on the market economy and the purchaser/provider split in commissioning services. The Conservative Government, elected in May 1979, took the view that the State was "organizationally inefficient and overly bureaucratic" (Miller & Ahmad, 2000, p. 3). It aimed to reduce waste by applying the market principles of efficiency, economy and effectiveness. The 1980s also witnessed a changing

view of society and citizenship, culminating in Margaret Thatcher's much quoted statement: "There is no such thing as society…" (Keay, 1987). Whereas the 1970s had been marked by a growth in state provision accompanied by economic difficulties and high unemployment, wealth creation became a priority during the 1980s for both the country and individuals. Acquiring wealth was viewed as increasing individual life choices (Yeatman, 2004, 2011) and individual prosperity was viewed as benefitting the whole society by enabling people to make personal provision for times of ill-health and old age. Collaboration again became prominent in the NHS and Community Care Act (HM Government, 1990), which required social services departments and local health authorities to engage in joint planning to develop community care plans. The political and legislative emphasis on collaboration did not imply the development of joint working was problem free, but rather "joint working between health and social services has long been fraught with problems arising from organizational, philosophical and cultural differences" (Miller & Ahmad, 2000, p. 4).

The inquiry into the death of Victoria Climbié (Laming, 2003) renewed attention on communication and collaboration between practitioners from different agencies. The Every Child Matters (ECM) consultation document (HM Treasury, 2003) emphasised interagency partnerships, cooperation and communication, and introduced a Common Assessment Framework (CAF), bringing practitioners, parents and other carers together in a 'team around the child' (TAC). The Warnock Report recommendation of appointing key workers was now fulfilled in the appointment of 'lead professionals'. The ECM consultation and subsequent legislation represented a major change in the perception of children's needs, in focusing on outcomes central for all children rather than adopting a needs-driven agenda (HM Treasury, 2003). While inclusivity was inherent in ECM, concern remained as to whether disabled children were receiving the support and services they required. A tension exists between specifically addressing the needs of disabled children and the potential risk of seeing disabled children as separate from other children (Goodley & Runswick-Cole, 2011). Further collaboration between education and children's services followed the demerger, in 2007, of the Department for Education and Skills and the creation of the Department for Children, Schools and Families (DCSF), with responsibility for child protection and education. Following the changes at national level, adult and children's social services were separated and education and children's services were merged into single directorates at a local level.

Collaboration and partnership is further reinforced in the special needs domain with the proposed replacement of statements of SEN with education, health and care plans (DfE, 2011; Secretary of State for Education, 2012).

Changing perspectives on disability

Perceptions of disability have changed considerably during the four decades since the enactment of the Chronically Sick and Disabled Persons Act 1970 (HM Government, 1970a). In 1970, the majority of children requiring learning support appeared to come from working class homes, possibly because middle and higher class parents contained their disabled children within the family rather than subject them to institutional care (Tomlinson, 2012). Children with sensory disabilities tended to attend specialist residential schools, receiving an education that enabled more academically able children to access public examinations and all children to receive training for future employment (Tomlinson, 2012). Roulstone and Prideaux (2012) suggest the primary approach to disability during this period was one of separation and containment tempered with benevolent philanthropy.

From the 1950s onwards, a number of national charities for disabled children were established by parents. Many of these organisations had the aim of ensuring appropriate care for disabled children and adults if family support was no longer available. At the same time the disabled people's movement emerged (Hodkinson, 2012). Disabled people rejected institutional care as the only option available to them (Roulstone & Prideaux, 2012) and drew attention to ways in which society disabled them. This laid the foundation for what became known as the social model of disability (Oliver, 2009, p. 43), and marked a move from philanthropic benevolence to the recognition of the right of disabled people to self-determination and the removal of structural barriers to full inclusion in society.

The Union of the Physically Impaired against Segregation (UPIAS) was arguably the most influential group in the UK promoting recognition of the part played by society and societal attitudes in disabling people. It stated:

> It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (Finkelstein, 2002, p. 1, citing the UPIAS Fundamental Principles of Disability 1975).

The social model of disability has become the prevalent model of disability, influencing social policy during the latter part of the twentieth century and into the twenty-first century and paving the way for the development of inclusive practices and anti-discrimination legislation. Underpinning the social model of disability and the disability studies' perspective is a clear allegiance to a social constructionist perspective. Whereas traditionally sociology and psychology located deficits in the individual, so that a child with a learning difficulty would be viewed as impaired, the social model challenges this view. The learning difficulty is viewed as "a construction that emerges through the interactions between the child, its teachers and others" (Burr, 2003, p. 8). Rather than locating disability in the person, the social model,

based on social constructionism, points to environmental and social factors that disable a person, suggesting that if these factors were removed or changed, the person would no longer be disabled. This view can be challenged as impairment effects remain despite structural changes (French, 2004a; Shakespeare, 2006; Shakespeare & Watson, 2002; Thomas, 2004, 2007).

The formulation of the social model did not mean the earlier medical, or deficit, model of disability was no longer relevant or that it ceased to exist. What is understood by the medical and social models of disability is contested (Smith, 2009), with some versions of the medical model using very similar language to that used in some versions of the social model, as in the suggestion that disability is caused by impairments (medical model) that "can be partially alleviated by changes in the social environment, so as to enable some degree of 'normal living' [social model]" (Smith, 2009, p. 22). Smith goes on to suggest that underpinning these changing perceptions of disability is a notion of 'normal living' and a proclamation of the right of disabled people to engage in that 'normal living' alongside adults and children who are not disabled. It is that claim to a right to participate in the mainstream that has influenced the agenda for inclusion, which has also shaped the special needs domain.

Although the terminology of SEN was influenced by the burgeoning disability movement in removing medical language from the determination of appropriate educational provision (Warnock, 2010), in practice, provision for children with special needs continues to be dependent on medical diagnosis and specialist assessment of needs (Goodley & Runswick-Cole, 2011; Hodge & Runswick-Cole, 2008; Todd, 2007, 2011). The legal definition of disability, focuses on impairment, defining a disabled person as having

> …a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities (HM Government, 1995, p. 1 and HM Government, 2010, p. 4).

Children have SEN if they

> …have significantly greater difficulty in learning than the majority of children; or have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority… (DFES, 2001, p. 6).

Similarly, children qualify for receipt of the Disability Living Allowance if they

> …need a lot more help or supervision than other children of the same age… (Directgov, 2011).

Although the social and medical models can be placed in apposition to each other, in practice it is not so straightforward. Whereas Goodley and Runswick-Cole state:

> The Disabled People's Movement has politicised disability and has shifted the attention away from 'deficit' models of bodies and minds… (2011, p. 74).

Thomas (1999, 2004, 2007) speaks of impairment effects, French describes the pressure she came under to deny her visual impairment (French, 2004a) and the barriers faced by other visually impaired professionals (French, 2004b) and Shakespeare (2006) points out that what is appropriate and enabling for a person with one type of impairment might be highly inappropriate and disabling for a person with different physical, mental or neurological difficulties.

The language of special needs and disability

Changes in the perception of disability are reflected in changes in the language used when speaking of disability and impairment. UPIAS introduced the use of the term 'disabled people', replacing the term 'the disabled', which was in common usage at the time. As explained by Goodley and Tregaskis, the terms

> …*disabled people*, *disabled children* and *disabled families* are chosen by proponents of the social model…[as they foreground]…the sociopolitical nature of disability: People with impairments are threatened with being disabled by society (2006, p. 631, emphasis in the original).

This usage has not been adopted universally, the People First movement, which is more prevalent in North America than the UK, preferring the term 'people with disabilities'. Changes in language and terminology do not of themselves imply changes in attitudes or greater understanding of disability rights or fewer societal obstacles to full inclusion in the community (Haller et al., 2006).

Not only is the language of disability conflicted, but also the language of 'special needs' is problematic. Corbett (1996) identifies various discourses influencing the language and practice of special needs, each of which can be conceptualised as a *field*, or subsystem, within the broader special needs domain. During the 1950s and 1960s, psychology had a pre-eminent position, fulfilling the purposes of determining the boundary between those children perceived to be 'backward' and those who experienced difficulty learning for other reasons, and determining the best type of educational placement for children with different types of need. Corbett also identifies a tension between sociological and psychological discourses since the 1970s, the latter being about identifying the most appropriate placement whilst the former recognises the different status attached to different types of school. In practice, the best placement may be considered to be a special school, but special schools are viewed as low status and segregationist, so supporting a child by placing them in a special school, might also be viewed as reducing the child's potential options both educationally and in terms of their future life choices. Further, philosophical discourses challenge the words that are used

in relation to special needs, asking questions such as what is meant by 'normal' and by 'special'? Cutting across the psychological, sociological and philosophical discourses is the political voice foregrounding the rights of disabled people and focusing on disabling attitudes and physical barriers.

Changing perception of special needs and the inclusion agenda

Unsurprisingly, the more general changes in public policy and the language and perceptions of disability have influenced the special needs domain and perceptions of special needs. The Warnock Report (DES, 1978) suggested 20% of children might experience individual difficulties, or special educational needs, at some time in their school career and most of these needs could be met within mainstream schools. It further suggested about 2% of the school population might require separate, specialist educational provision. Recent figures show 2.7% of all school pupils have a statement of SEN, indicating a high level of support needs, and a further 18.2% have SEN not requiring a statement (Ofsted, 2010). The same figures showing just over 1% of all school pupils were on special school rolls, but provided no indication of how many children are placed in special units in mainstream schools.

A surface inspection suggests that the numbers of children with SEN match the predictions of the Warnock Committee, but the reality is more complex as there have been changes in the population of children viewed as having special needs over the past four decades. The Warnock Committee was instructed to exclude from their discussion children

> …who suffered from nothing except social deprivation or those for whom, when they started school, English was not their first language (Warnock, 2010, p. 23).

However early criticism of the 1981 reforms focused on the failure of the Warnock Committee to recognise that some children's learning difficulties "might *not* primarily be the result of *individual* pupil disorders" (Lewis & Vulliamy, 1980, pp. 6, emphasis in the original) but might result from social and cultural factors. The link between social deprivation and SEN continues to be debated, the Ofsted review (2010) suggesting some children are inappropriately identified as having SEN because of their social circumstances, while Tomlinson (2012) suggests the link between social deprivation and SEN might have been stronger at the time of the Warnock Report than previously realised as, prior to the 1981 Education Act, many middle class and upper class parents made their own arrangements for children who were not developing typically, rather than make use of the facilities then available. This reflects my own experience, working as a social worker in a deprived area in the early 1970s, when a number of children known to me were placed in a residential 'open-air' special school, as an alternative to being received into the care of the local authority.

Some conditions, now considered special needs, were unknown, uncommon, or unrecognised as SEN in the 1970s. Whereas the Warnock Committee was instructed to "not include dyslexia as constituting a special need" (Warnock, 2010, p. 22), children with dyslexia and other "new disabilities" (Dyson, 1997), including AS/HFA, dyspraxia and AD(H)D now form a sizable proportion of children recognised as having SEN. However children with sensory and physical impairments, who would have attended specialist schools in the 1970s, are educated in mainstream settings and are recognised as having additional needs due to their impairments, but may not require statements of SEN. Parents may view a diagnosis as necessary for a child's special needs to be addressed (Jacobs, 2011), suggesting diagnosis is not only a medical process but also a political process, the appropriate label providing access to resources (Ahuja & Williams, 2010; Corbett & Norwich, 1997; Shakespeare, 2006). Rather than reducing the medicalisation of children, SEN terminology may have had a perverse effect as the assessment process and medical label may divert attention from the whole child (Kirby et al., 2005) to the child's diagnosis.

A further area of debate centres on the inclusion of children with SEN in mainstream classrooms. The Warnock Report and the 1976 and 1981 Education Acts laid the foundation for a movement from segregated schooling to the integration of children with SEN and disabilities in mainstream classrooms, but the disability movement promoted full inclusion (Goodley, 2011). In 1995, Michael Oliver, a leading proponent of the social model of disability, expressed the view that there was no continuing role for special schools in the twenty-first century (2009). The Salamanca Statement (UNESCO, 1994) and the Convention on the Rights of Persons with Disabilities (United Nations, 2007) state the right of children to a mainstream education in their home locality, irrespective of their disability. However, not all parents and practitioners welcome full inclusion. Some parents want their children educated in special schools and are frustrated when their child is refused a special school placement and placed in a mainstream classroom. There is continuing tension between the case for full inclusion and whether inclusion is appropriate for all children (Terzi, 2010).

The coalition government, introducing its consultation on SEN reform, states: "We will remove the bias towards inclusion" (DfE, 2011, p. 5). The previous administration told the House of Commons Education and Skills Committee it did not have "a policy of inclusion that is resulting in the closure of special schools" (House of Commons Education and Skills Committee, 2006, p. 5). However, the Select Committee concluded that there was an agenda for inclusion, suggesting government policy did not reflect the SEN and Disability Act (HM Government, 2001) and the SEN Code of Practice (DFES, 2001):

> The Government should be up-front about its change of direction on SEN policy and the inclusion agenda, if this is indeed the case, and should reflect this in updated statutory and non-statutory guidance to the sector (House of Commons Education and Skills Committee, 2006, p. 6).

Runswick-Cole (2011), following ideas voiced by Dyson (2001), suggests there is a need to rethink our understanding of inclusion, calling for a "cultural shift to promote inclusion in education" (p. 117) and argues that the focus on targets has resulted in many "children who do not or cannot fit the system [being] pushed out of mainstream environments" (2011, p. 117). On the other hand, Hodkinson also calls for a rethinking of inclusion, but questions whether inclusion has ever been a reality, suggesting emphasis be placed "upon the maintenance of individual identity" which ensures "individual children and their families can choose when, where, how and even indeed *if* they want to be included at all" (2012, p. 10, emphasis in the original). This ongoing debate impacts on practitioners, parents and children and leads to some struggles and fights in the special needs domain.

Concluding reflections

This chapter places the special needs domain in its legal, social and political context. During the past four decades, the domain has been subject to the influences of legislation, changes in societal attitudes and changes in practice.

Although there was a strong emphasis on collaboration and partnership in joint planning, particularly during the 1970s, 1990s and the last decade, this was tempered by an emphasis on market principles in the 1980s and again under the current government. The structural separation of health and education, both administratively and financially, results in multiple assessments, potential confusion when practitioners from different agencies hold different views on what is in a child's best interests, and the provision of some services being dependent on payment from one public body to another. It is possible the proposed EHCP will ameliorate some of these issues, but at the time of writing this is by no means certain.

The social model of disability has provided a framework for changing perceptions of disability, recognising the disabling effect of society, but there is a danger of viewing all disabled people as the same, rather than acknowledging the differing effect of impairment on different individuals. The social model underpins the move from segregated education to integration of disabled children into mainstream schools leading to full inclusion, but it can be argued that some children benefit from being educated separately from typically developing children. However, it is difficult to argue that a segregated placement is in a child's best interests when the emphasis in SEN education is inclusion and the child is intellectually able to follow a mainstream curriculum.

Despite the social model shifting the focus from impairment, access to special needs support is dependent upon identifying a child's needs and impairments. Whereas the introduction of the term SEN was designed as a move away from pejorative labelling, it has introduced new categories of SEN, some of which did not exist or were unrecognised at the time the

legislation underpinning special needs provision was enacted. The new disabilities include AS/HFA and as a group, the diagnosis of these 'new disabilities' continues to be contested.

The recommendation of the Warnock Committee to appoint key workers for children with SEN was not enacted at the time, but under the Common Assessment Framework (CAF) some children with additional needs have a "lead professional" appointed. However, not all children with special needs have such a person appointed, leaving a potential void as will be seen in the account of a child with AS/HFA excluded from school that is discussed in Chapter Eight.

These themes are returned to in the next chapter, where I consider the literature relevant to struggle and fight in the special needs domain, and in Chapters Six to Eight where I report and discuss the findings of the empirical study undertaken during this research.

Chapter Four

Literature Exploring Aspects of Struggle
and Fight in the Special Needs Domain

In the last chapter, I focused on the socio-legal-political aspects of the development of the special needs domain and the influences shaping it. In this chapter, I turn to the research literature about the special needs domain to explore how it can assist understanding of the 'struggle/fight metaphor'. Research in the special needs domain tends to focus on specific aspects of special needs, some studies addressing the 'big picture' while others explore details, including some that can be understood as 'personal troubles'. In adopting a *systems* approach, both approaches are relevant to understanding the meanings of 'struggle' and 'fight' from different perspectives of the special needs domain.

The discussion in this chapter is divided into three sections. Firstly, I consider structural aspects of the domain, extending the discussion of Chapter Three, and addressing those of my research questions concerned with the relationship between the systems comprising the domain and the 'struggle/fight metaphor'. In the second part of this chapter, I consider studies focusing on the parent/practitioner relationships and thirdly, I focus on the experience of parenting children and young people with special needs, in particular those with AS/HFA. These latter sections relate to my research questions about how the 'struggle/fight metaphor' is experienced.

The special needs domain as a whole *system* – research pertaining to 'the big picture'

Historically, much of the general literature relating to special needs has focused on special *educational* needs, be it the formal policies and processes for assessing learner needs or the practice implications of teaching children and young people deemed to have SEN. More recently studies have taken a broader approach, recognising the implications special needs may have for the lives of children beyond school. Much of the impetus for this broader approach stems from the Every Child Matters consultation (HM Treasury, 2003) and subsequent legislation (HM Government, 2004a), leading to a partial adoption of the terminology of 'additional needs' (Marrable, 2011) and a common assessment framework (CAF) with renewed emphasis on collaboration amongst practitioners from different agencies and professions (HM Government, 2004b). Collaborative working continues to be emphasised in the 2011 review of the SEN system (DfE, 2011) and subsequent draft legislation (Secretary of State for Education, 2012).

Other research focuses on organisational and structural aspects of the special needs system. Some studies explicitly refer to *systems* approaches (Edwards et al., 2009; Russell, 2003; Truss, 2008), but it is more usual to find studies refer to *systems* concepts, such as boundaries and boundary working, without necessarily placing these concepts in a *systems* framework. In this section, I consider boundaries and collaborative working, obstacles to collaborative working and the use of boundary objects to facilitate boundary working and relate these to the struggle/fight metaphor.

Boundaries and collaborative working

The special needs domain is comprised of a number of separate *fields* or inter-related *systems* (Chapter Three, Figure 2). The boundaries separating *fields* or *systems* are socially constructed, malleable and "likely to be complex, unstable and negotiable" (Edwards et al., 2009, pp. 37-38) and less dominant groups may be marginalised by the positioning of a boundary (Midgley, 1992; Midgley et al., 1998). In order to collaborate with practitioners, it is necessary for parents to negotiate boundaries, but parents of children with special needs report feeling marginalised in their relationships with practitioners (Brett, 2002; Cole, 2005; Coyle, 1999; Hess et al., 2006; Hodge & Runswick-Cole, 2008; Keenan et al., 2010; Todd & Jones, 2003), and may view themselves as powerless (Gazeley, 2012; Todd & Higgins, 1998). Such exclusion may not be intentional. When practitioners engage in developing interagency working practices in boundary zones, they

> …had to become comfortable with inter-professional negotiations before they could negotiate their position vis-à-vis the expertise of parents (Edwards & Kinti, 2010, p. 129).

However, parents may be excluded from some discussions, as when

> …all participants spoke at length, and with complete unity, about the need to exclude parents and carers from contributing to their children's common or inter-professional assessment (Edwards et al., 2009, p. 90).

While not excluding parents, there is evidence of some practitioners expecting parents to adopt a passive role in negotiations about their children (Tveit, 2009). Boundary working is energy intensive (Edwards et al., 2009; Edwards & Kinti, 2010) and stress, overwork and anxiety can lead practitioners to retreat from boundary working

> …into their individual professional silos, where there is safety, clear limits, recognition of professional value and license to work autonomously (Hall, 2005, p. 190).

Systems practitioners focus on identifying and constructing models with different boundaries in order to differentiate what is included within the *system* from entities residing in the *system* environment that are not part of the *system*, but may impact on the *system* or influence it. The term 'boundary' is used in different ways in studies relating to special needs

and sometimes the term is used in more than one way within the description of a single study. Some studies focus on boundaries as they relate to the relationship between parents and practitioners (Pinkus, 2003, 2006; Russell, 2003; Todd & Higgins, 1998) or communication between different practitioner groups (Dunsmuir et al., 2006; Hall, 2005), while others focus on institutional or agency boundaries, addressing obstacles to collaborative working (Edwards et al., 2009; Marrable, 2011), or crossing boundaries as when transitioning between services (Goodley & Runswick-Cole, 2011).

Miller and Ahmad (2000) draw attention to the emphasis on collaboration and partnership in legislation and public policy documents relating to the education, health and social care sectors since at least the late 1960s. Despite the formal structures designed to enable partnership working, in practice there is confusion about what partnership and collaboration entails and reports of difficulties crossing boundaries:

> Joint working between health and social services has long been fraught with problems arising from organizational, philosophical and cultural differences (Miller & Ahmad, 2000, p. 4).

Various arguments are posited as to why collaboration is advantageous (Atkinson et al., 2002; Miller & Ahmad, 2000). Some are based on assumptions that collaboration and working together avoids duplication of services and saves money, while sharing expertise. Others focus on the benefits of viewing recipients of services holistically, providing responses and resources that take into account the whole person/family in their familial and community context. Collaborative working can enable skill sharing and knowledge development between practitioners from different professions and agencies leading to the development of interdisciplinary communities of practice (Lave & Wenger, 1991; Lave et al., 2005; Wenger, 1998). The places where *systems* intersect, or 'boundary zones', (Konkola et al., 2007) may be experienced as neutral spaces "…where practitioners…share meanings, begin to understand the specialist strengths of others, and explore new identity positions… (Edwards et al., 2009, p. 39), or as places where dissonance occurs as social agents struggle with different ideas, concepts and ways of working (Daniels et al., 2010).

Different forms of collaborative working

Just as boundaries are spoken of in different ways, collaboration is also given different meanings in practice (Sloper, 2004). It can refer to institutional collaborative activities, involving interagency and interprofessional collaboration (Miller & Ahmad, 2000), partnership, including synergy, budget enlargement and transformation (Mackintosh, 1992), and the practice of partnership, focusing on the work of individual practitioners (Clark, 1994; 1997; Rosenfield, 1992; Sands, 1993). There are different models of partnership in practice, including team working and multidisciplinary, interdisciplinary and transdisciplinary practices (Opie, 1997). According to Watson et al. (2002), practitioners in interdisciplinary teams made

independent assessments and shared their recommendations to develop a programme for intervention and practitioners in multidisciplinary teams worked together to address problems, but the focus was on the needs of the child, giving little attention the needs or views of the whole family. In transdisciplinary working, there was a significantly higher level of integration of work between practitioners from different disciplines and agencies, the development of common values and a common language within the team, and parents were included as full members of the team, with full account being taken of their views and needs.

Not all types of interagency working demonstrate team working (Edwards et al., 2009). Multi-professional teams might form a permanent work unit, or be comprised of individuals, from different agencies, who meet together regularly as a team, but also work separately. Co-location had little effect on collaborative working, but when practitioners came together, either informally or through specific initiatives, collaboration was evident (Edwards et al., 2009).

Boundary working in the special needs domain

Children and young people with special needs and their families have to relate to different agencies and to work across boundaries. They may be involved with practitioners in health, education and social care services as well as receiving support from community organisations and, possibly, also engaging with practitioners in private practice. Each of the public bodies has different boundaries in determining eligibility for access to services based on different statutory frameworks and on local policies and practice. A child recognised as disabled, by receipt of DLA, and having special needs, through a statement of SEN, may not be eligible for support from the social work team responsible for disabled children (Goodley & Runswick-Cole, 2011). In order to obtain a service, parents may exaggerate a child's needs to

> …construct a version of impairment that is at odds with the ways those children are constituted in the family…[as assessment focuses]…on the child's deficits and the parents' parenting capacity, rather than any focus on the social barriers to the child and family's participation in society (Goodley & Runswick-Cole, 2011, p. 78).

Marrable observes a tendency of services to prioritise the highest categories of risk, leading to children slipping

> …through the cracks into physical, psychological, or social harm…[a situation exacerbated by]…lack of cooperation between services…proving an hindrance to early intervention (2011, p. 17).

The transition from child to adult services is a particular area of tension (Goodley & Runswick-Cole, 2011). Different service providers have a different age at which a young person transitions to adult services, and there may be variations within a service; in education a statement of SEN is maintained until age nineteen if a young person continues into the school sixth form, but if the same young person continues their education in a

college of further education, the statement ceases to be maintained when the young person leaves school. Adult services may have different criteria from the equivalent children's service for determining who qualifies to receive a service, resulting in young people and their parents feeling unsupported when they no longer qualify for support or services they are accustomed to receiving.

Obstacles to collaborative working

There are many obstacles and challenges to interagency working including financial, management and communication issues as well as professional and organisational cultures, competing priorities and roles and responsibilities (Atkinson et al., 2002). Even when there is a will to work together there is a tendency for the success of multi-agency working to be a function of individual practice rather than something that can be imposed on agencies and individual practitioners (Atkinson et al., 2002; Miller & Ahmad, 2000). Government directives were instrumental in enabling some developments but were counter-productive in others (Atkinson et al., 2002).

Structural boundaries can present problems for interagency working at both an organisational and practice level. The separate budgets and management structures of education, health and social care services can be a disincentive to joint working. When agencies agree to joint fund a project or pool their budgets, issues arise over which agency or department is accountable for public resources (Atkinson et al., 2002). If resources are constrained, elected members of health or local authorities may question why they are handing over funds from their budget to others to administer (Atkinson et al., 2002), a finding that could have implications for the implementation of the Education, Health and Care plans proposed in the review of SEN (DfE, 2011), at a time when all public bodies are facing budget cuts and legislation has already been passed making substantial changes to the health service (HM Government, 2012a).

Additionally, when resources are under pressure it can be risky for agencies to work together successfully as their achievements may make it difficult to justify their separate existence (Atkinson et al., 2002; Miller & Ahmad, 2000), creating a perverse incentive not to collaborate. Policies driving collaborative working are predicated on the expectation:

> Effective partnerships can be expected to generate information sharing, improved communication, a better understanding of what each stakeholder can offer, the avoidance of duplication inefficiencies, and the identification of opportunities for the effective sharing of resources (Miller & Ahmad, 2000, p. 12).

If such effectiveness is achieved, there is a risk of job losses resulting from agency mergers and the concomitant loss of the expertise of those practitioners not employed in the new structures.

Obstacles stemming from professional values

Professionals from different agencies can find themselves placed in a position of conflict if their values and those of their employer conflict with the values and objectives of a multi-agency initiative. An agency may place an obligation on a service user that is inconsistent with the ethos of another agency or profession. If multi-agency working is made a priority "issues of professional territoriality, or pursuing an agency specific aim" need to be put to one side (Atkinson et al., 2002, p. 145), presenting challenges for joint working in the special needs domain, where education services are for all children, health services focus on children who are sick or disabled, and social care on children in need of protection or who are severely enough disabled to be eligible for support services (Goodley & Runswick-Cole, 2011).

Different practitioner groups use different specialist language (Housley, 1999, 2000; McCartney, 1999). Research in hospital settings found

> …social work talk belonged in social work records, psychiatric talk belonged in medical records, and nurse talk belonged in nursing records (Prior, 2004, p. 86).

If there are difficulties within a single institution, how much more difficult to decode the 'jargon' in community settings when working collaboratively with teachers, doctors, psychologists, therapists, social workers, bureaucrats and paid staff and volunteers from nongovernmental organisations. The different language used by practitioners from different disciplines is also problematic for parents who need to communicate with different practitioners in different settings (Rogers, 2007). Paradoxically, in some settings where role blurring between different disciplines is evident, some practitioners become "more insistent on separate professional identities" (Brown et al., 2000, p. 425).

Government targets can also present an obstacle to multiagency working if decisions have to be made as to whether to invest employee time and other resources on interagency working, or to prioritise meeting government targets such as reducing waiting lists or meeting literacy and numeracy targets, especially when failing to meet targets can result in sanctions and financial constraints and staffing numbers preclude doing both (Atkinson et al., 2002).

Boundary Objects

Boundary objects are artefacts that are considered able to facilitate communication across boundaries and "empower members of different communities to transfer their own knowledge" (Fox, 2011, p. 72) and allow different communities of practice (Lave, 1991; Wenger, 1998) to learn about each others' perspectives and share meaning. In the special needs system, there are many artefacts including diagnostic reports, Individual Education Plans (IEP) and statements of SEN that are shared between parents and practitioners from

different disciplines. The introduction of boundary objects may both exacerbate and ameliorate difficulties (Fox, 2011). Although many types of special needs and disabilities may be formally diagnosed soon after birth or during the early years, children with ASCs, especially those with AS/HFA, tend to receive a diagnosis relatively late, and often when they are already in the school system (Howlin & Asgharian, 1999). Very often parents are anxious to receive a diagnosis for their child and the diagnostic report provided by the medical team is prized (Jacobs, 2011), but the report may be viewed differently by the school, which may not share the medical perception of the child's needs, and faces the dilemma that addressing one child's special needs may mean reducing support to another child with special needs. The formal diagnosis of a child might also be a first step to the time and resource intensive process of a formal assessment of SEN, involving negotiations with the local authority to ensure appropriate provision is put in place.

In interprofessional and interagency working, boundary objects may not always be tangible. Practitioners working in different agencies and coming from different backgrounds can develop a shared value system and resources (Edwards & Kinti, 2010). These shared resources may not be artefacts, but

> …the specialist concepts and insights that are specific to different professional practices and cultures…[which]…are embedded within their practices and carried implicitly in how they construct the categories that shape their work (Edwards & Kinti, 2010, p. 127).

People are also resources. Relational agency is

> …a capacity that involves recognising that another person may be a resource and that work needs to be done to elicit, recognise and negotiate the use of that resource in order to align oneself in joint action (Edwards et al., 2009, p. 40).

Appreciating the skills and expertise of practitioners from other disciplines is essential to effective collaborative working.

Parent partnership, power and expertise

Parent partnership has two very different meanings within the special needs domain. It refers to the parent partnership schemes that were first set up in 1994, and, which, under the Special Educational Needs and Disability Act 2001 (HM Government, 2001), local authorities are responsible for funding and ensuring parents can access (Rogers et al., 2006). Parent partnership schemes are not uncommonly located in local authority premises, but are not part of the local authority, and the advice they give is 'arms length' from the local authority. Alternatively, 'parent partnership' refers to the relationship between parents and practitioners from different services working together to address a child's needs. This latter meaning is the one used here.

Parent and practitioner partnership

The relationship between parents and practitioners is inevitably complex. Although the SEN Code of Practice (DFES, 2001) can be cited as endorsing partnership, it also refers to parents as 'informants' (Hodge & Runswick-Cole, 2008), weakening the concept of partnership by placing parents in a different position from practitioners. Hodge and Runswick-Cole follow Cole (2004) in suggesting that despite the emphasis on partnership in policy documents:

> The term 'partnership' is often loosely defined and that, despite the calls for parent-professional partnership, there are inherent tensions within the current policy.. (Hodge & Runswick-Cole, 2008, p. 638).

The language used implies not only inequality of power with decision makers, but parents are differently positioned, as requiring support, suggesting both a possible underlying deficit in parents and the expectation that parents cannot really be equal with practitioners. Further, the Code of Practice endorses seeking advice from a range of practitioners, while failing to recognise and endorse seeking the 'expertise' of parents in the same way (Hodge & Runswick-Cole, 2008).

Todd and Higgins state: "the relationship between parents and professionals…can never be an equal one" (1998, p. 228). Brett advocates the development of new forms of working alliance between parents and practitioners as "parents rarely enjoy an equal relationship with professionals" (2002, p. 827), but parents feel side-lined and ignored in meetings with those responsible for making decisions about their children (Brett, 2002; Rogers, 2007; Truss, 2008) and some parents are unwilling to engage in such meetings as they suspect their views will not be heard (Preston, 2005). Underlying difficulties in parent/practitioner relationships are issues of expertise and of power. The relationship between parents and practitioners is an uneven one, in which practitioners occupy a dominant role where they can exclude children from school, ration resources and services, observe and exercise surveillance over parenting styles and make moral judgments (Todd & Jones, 2003). Hess et al. speak of the responsibility of educational practitioners to redress this power imbalance being "knowledgeable about parental needs and perspectives" (2006, p. 150). Parents can be disempowered as they and their children are objectified, choices are reduced and it becomes less possible to resist the labelling inherent in discourses (Coyle, 1999).

Knowledge and expertise

It is sometimes assumed that parents do not share practitioners' expertise, but Todd and Higgins found

> …if you try to define the knowledge of parents and that of professionals, the list will contain very similar items, making statements about knowledge difference problematic (1998, p. 228).

They suggested a more useful approach was to explore the different types of involvement parents and practitioners have in the life of a child. Whereas parents have a long-term affective relationship with their child(ren) and in-depth knowledge of their own child(ren), practitioners have a specific role in relation to a child or group of children rather than in-depth expertise of a specific child. Practitioners' expertise is based on their previous experience of working with children with similar conditions and draws not only on personal experience but also the shared experiences and knowledge of other practitioners. It may not be acknowledged that many parents do have knowledge and expertise that extends beyond what they have learned from addressing the needs of their own child(ren), including knowledge and information gained from other parents, practitioners and more general exploration and reading (Fleischmann, 2005). This knowledge forms part of the social capital of parents. Possession of capital is a marker of power (Bourdieu, 1998), but the tendency for practitioners to privilege their knowledge over that of parents, devalues the power and expertise of parents and makes it difficult for them to enter into a dialogue of equals (Elsworth, 2003).

Many parents do express a desire to participate in decision making in relation to their children, and

> …would welcome being able to make informed decisions about the design of their child's treatment and support…[but education and health authorities]…made limited mention of involving parents in this way" (Bryson et al., 2008, p. 8).

In practice, parents have greater knowledge of some interventions and approaches than practitioners (Keenan et al., 2010; Starr & Foy, 2010). The problem parents experience in entering into a meaningful partnership with practitioners is not limited to any one setting. It may extend to being kept in ignorance of their child's diagnosis (Todd & Jones, 2003), perhaps on the premise that parents need to be protected. Parents may feel depersonalised by practitioners, as when they are referred to as 'mum' rather than by their name, resulting in:

> Parents feeling stigmatised, patronised, conscious of not being taken seriously, constantly judged, 'under pressure to be a good parent', powerless and vulnerable (Brett, 2002, p. 833).

Privileging of some forms of knowledge over others extends beyond parent/practitioner relationships to relationships between practitioners from different disciplines where good working relationships may be apparent at a practice level, but less evident at more senior levels in the hierarchy (McCartney, 1999). These difficulties may only be overcome through a commitment to collaboration from senior managers and through the development of appropriate enabling and facilitation mechanisms (Sloper, 2004).

Understanding power and agency in the special needs domain from a Bourdieusian perspective

Bourdieusian concepts of habitus, the dispositions of an individual based on their socialisation and life experiences, and social capital, the network of contacts and groups an individual belongs to, can be useful in understanding the relative power of the different social agents – parents and practitioners – involved in the processes of the special needs domain.

Nind explores the effect of capital on parental interactions with health, education and social care practitioners contrasting parents with a strong social network who are relatively affluent with others lacking these resources, and observes:

> The less capital one has, the less comfortable one is likely to be with taking on those imbued with cultural, economic and symbolic capital (2008, p. 92).

Drawing on Bourdieusian metaphors that liken the *field* of struggle to the sports field, Nind (2008) and McKeever and Miller (2004) identify 'getting a feel for the game' and developing strategies that comply with the rules of the game as important elements in engaging in dialogue in order to achieve goals. Parents struggle because there is "no other option" (Nind, 2008, p. 96), sometimes recognising their options are limited and choosing to acquiesce "to dominant players in the fields of paediatric medicine and long-term care" (McKeever & Miller, 2004, p. 1178).

In an investigation of parental communications with their children's schools, Vincent and Martin (2000, 2002) differentiate parents into three groups: those highly involved with the school and "not willing to leave education to the school [leaving] as little to chance as possible where their children's educational prospects were concerned" (Vincent, 2001, p. 349); those parents who are less involved with the school, but attend parents evenings and contact the school if concerned about their child's welfare, and are "less knowledgeable about educational issues…[and]…felt failed by their own schooling and wanted their children to do better than they did (Vincent, 2001, p. 351); and a third group of parents who are described as having limited cultural capital in regard to education and show a "discernible reluctance about participating in school meetings…[and were]…disappointed and disillusioned with schools" (Vincent, 2001, p. 351). Whereas parents in the third group rarely communicated with the school, remaining silent even when angered by school actions, parents in the other groups engaged with the school using various communication techniques including dialogue and making formal protests. If the situation was not resolved, parents with greater social and cultural capital used their resources to by-pass the system, making private arrangements to meet their children's needs or moving the child to different schools (Vincent & Martin, 2002).

These studies appear to support the suggestion that the 'middle-classes' are able to leverage a disproportionate allocation of public service resources, a perspective further supported by Matthews and Hastings (2012), who suggest that the habitus and capital of the middle-classes places them in a favourable position when communicating with practitioners as they share a similar habitus. Curiously, it would appear "those in the middle" (Matthews & Hastings, 2012, p. 10) also have a higher need to complain than those of lower economic status, who expect least and complain least, and those with high-economic status, who can utilise their capital to ensure their requirements are met. Those in the middle have the cultural capital and disposition that enables them to complain "and needs which make them reliant on public services" as they do not have the economic capital to meet those requirements themselves (Matthews & Hastings, 2012, p. 10). Although the cultural capital and habitus implicit in knowing the rules of the game is important, Matthews and Hastings suggest that knowing the rules is not enough of itself as "complaining in the 'right' language *can* rather than *will* be important" (2012, p. 15).

Much of the literature speaks of parents when discussing collaboration with practitioners, not differentiating mothers and fathers. Most of this work is undertaken by mothers, irrespective of whether a child has special needs (Reay, 1998). Mothers of disabled children are at times stereotyped as over-protective, uncooperative with practitioners and tending to be unrealistic about the nature and severity of their child's disability to the extent of being viewed as being in denial, but McKeever and Miller (2004) offer a contrasting perspective, suggesting that when mothers' behaviour is viewed through a Bourdieusian lens it is fully rational as mothers use what capital they have, or can assimilate from others, to position themselves and their children better. A mother retains an acceptable identity by being seen to be a good mother who is doing all that is necessary for her child. Similarly, a child is better positioned by focusing on their achievements rather than their impairments. However, parents experience tension when there is a conflict between a positive presentation and needing to emphasise the child's impairments in order to gain support (McKeever & Miller, 2004, p. 1188). This can be contrasted with Larson's perspective that parents embrace a paradox, accentuating positive achievements while accepting the limitations imposed by their children's impairments, in order to energise themselves to ensure everything possible is done in order to enable their children to achieve their potential (Larson, 1998).

The experience of parenting a child with special needs

Just as being in contact with a network of practitioners is a defining characteristic of being the parent of a child with special needs (Rogers, 2007), so is struggle. There can be a tendency to ask parents of disabled children how they are coping (Yuan, 2003), using the same language as that used towards recently bereaved people, but an essential difference

between bereavement and parenting a child with special needs is that a bereaved person has lost somebody, but parents have lost the expectation of an 'ideal child' (Bruce & Schultz, 2002). This is graphically described in *Welcome to Holland* (Kingsley, 1987), a short story found on many special needs websites, where a long-desired for and planned holiday is supplanted when the plane lands at a different destination, requiring new maps and plans. Bruce and Schultz term this a 'non-finite' loss, which they define as an "enduring sense of loss precipitated by a negative life event or episode that usually retains a physical presence, a psychological presence, or both" (2002, p. 9). Following Bowlby (1953), Bruce and Schultz suggest that parents engage in an ongoing search for the missing object, the lost child, and may be seen by practitioners as being in denial, or failing to accept their child's disability. An alternative view suggests that rather than maintaining hope of the return of the 'ideal child', mothers of children with ASCs redefine their expectations to overcome dissonance (Tunali & Power, 2002). Studies of families with autistic children found an increasing acceptance of the child's condition over time (Gray, 2006; Myers et al., 2009; Sirota, 2010).

Although parents may be aware of their child's difference, parents only actually know their child is different when the child is pronounced 'impaired' by a clinician (Vehmas et al., 2009). Some parents of children with AS/HFA speak of relief at receiving a diagnosis and having an explanation their child's differences (Midence & O'Neill, 1999; Osborne & Reed, 2008), while others speak of the shock of the diagnosis and facing the reality that their child really is different from typically developing children (Fleischmann, 2005; Keenan et al., 2010; Mansell & Morris, 2004; Nissenbaum et al., 2002).

Parenting children with AS/HFA

Raising children with special needs is known to be stressful. Some authors suggest raising a child with an ASC may be more stressful than raising a child with other disabilities (Glazzard & Overall, 2012; Gray, 2006; Myers et al., 2009). The literature specific to the coping strategies of parents of autistic children tends not to distinguish between different types of ASC (Bristol, 1987; Gray, 1994; Snell & Rosen, 1997), possibly because the studies were undertaken at a time when fewer children were being diagnosed and AS/HFA was less recognised (Timimi et al., 2011), but it may also be because parents of children with AS/HFA refer to their children as autistic (Marshall & Long, 2009)[6]. Even when not specifically stated, the context makes it clear that many studies included children with AS/HFA and their families within the sample.

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[6] The article, based on Marshall's doctoral thesis, gives no indication of the precise diagnosis of the children of the participants in her study, referred to as co-investigators, though she indicates in her thesis that parents tend to use the term 'autism' generically, and in a private communication wrote: "Because I was interested in how parents construct their situations, I included participants who self-identified as the mother of a child with autism, regardless of whether the child had autism or Asperger's." In fact, her sample included mothers of children with Asperger's syndrome and mothers of children with classic autism, and it is likely that this is the case in many other studies where there is a lack of precision over the diagnostic labelling of children. Some parents may also use the 'autism' rather than 'Asperger's' label because Asperger's is sometimes described as a mild form of autism, and because of high profile media coverage of some people with a diagnosis of Asperger's, but these latter points are supposition.

Sociological studies have explored the way families with a child on the autism spectrum organise family life and the different ways in which parents make sense of their child's condition (Gray, 1994; Tarakeshwar & Pargament, 2001). In families where there is a disabled child, including a child with an ASC, very often the mother becomes the primary carer, even if this was not what the parents planned initially (Altiere & von Kluge, 2009; Glazzard & Overall, 2012; Gray, 2003; Marshall & Long, 2009). It is unclear whether parents of different genders adopt different coping mechanisms (Altiere & von Kluge, 2009; Hastings et al., 2005). In an Australian study, Gray (2003) reports that in families where there was a child with AS/HFA, the mother tended to become the primary carer, taking the major responsibility for taking the child to medical and other assessments, while men tended to become increasingly involved in their work lives, sometimes doing excessive overtime, and developing a role separate from the domestic life of the family.

Exclusion, stigma and marginalisation

There is evidence to suggest that, despite disability discrimination legislation, children with special needs, including those on the autism spectrum, continue to be excluded from school activities. Parents may be asked to keep a child at home on occasion, or a child may leave school early in order to avoid specific activities. Although such absences from school, if made at the request of the school, should be recorded as exclusions, there is a tendency to regard them as informal absences (Reid, 2011). The same research also found that on occasion risk assessments are written in such a way as to prevent children with AS/HFA being included in residential and other activities alongside their peers.

In an exploration of the experiences of felt and enacted stigma (Goffman, 1963) of families with children diagnosed with AS/HFA, Gray (2002) found parents experienced difficulty interpreting the responses of strangers to their child behaving in unexpected ways in public places. In a study of the public surveillance of children's behaviour in public places, Ryan (2010) describes the actions taken by parents of children with ASCs in order to deflect the public gaze from themselves and their child, including 'outing' their child or handing the stranger a card giving a brief description of autism and why the child is acting as they are. The families of children with AS/HFA live more restricted lives than other families (Glazzard & Overall, 2012). This may a reaction to the experience of enacted stigma, which Gray (2002) suggests takes the form of an absence of invitations to social gatherings, hostile staring by others, and rude comments by strangers about the child's behaviour, but such restricted lives may also result from the lifestyle of such families:

> The activities of an autism household are directed by the strict routines governing all aspects of life, variations on which can have disastrous consequences (Farrugia, 2009, p. 1017).

The social life of all family members is affected by autism in the family, not only that of the autistic child. Some research suggests that the social and friendship circles of families with children with an ASC may consist mainly of similar families, as earlier friendships and social contacts are lost because the family no longer occupies the same social space as parents of typically developing children (Farrugia, 2009; Gray, 2002).

AS/HFA is sometimes described as a mild form of autism and may be diagnosed later than other autism spectrum conditions (Glazzard & Overall, 2012; Howlin & Asgharian, 1999; Wilkinson, 2010). Children with AS/HFA may not be impaired in the same way as children with classic autism, but the descriptor 'mild' can be something of a misnomer as these children have social communication difficulties that cause them to be severely disabled socially. "The normal physical appearance of children diagnosed with ASD can make interpreting their disruptive behaviours difficult and ambiguous" (Farrugia, 2009, p. 1016), resulting in very real difficulties for children and young people. Additionally these children are at greater risk of being subject to negative responses from strangers as they tend to engage in more social activities than children with more severe forms of autism (Gray, 2002).

Metaphors of struggle and fight

Parents use "combative metaphors and descriptions to describe their attempts to gain services for their children" (Crawford & Simonoff, 2003, p. 484). They speak of themselves as being in an adversarial relationship with the practitioners employed to ensure their children with special needs are appropriately supported (Geldard, 2004; Marshall & Long, 2009; Paradice & Adewusi, 2002; Woodgate et al., 2008), describing their efforts "in terms of a 'war', a 'struggle', a 'combat', a 'battle' or a 'fight'" (Fleischmann, 2005, p. 305). In a study of parents known to have had a conflictual relationship with the local authority in relation to their child's schooling,

> …this metaphor of warfare was a recurring one throughout the research. Many parents referred to battles, enemies and aggressive conflicts, frequently militarising the adversarial relationships between family and school (Duncan, 2003, p. 346).

As well as being in a struggle, parents speak of struggling to access provision to address their child's needs (Bryson et al., 2008). Parents may perceive themselves as having no voice and experience difficulty advocating effectively on behalf of their child (Hess et al., 2006). Fighting is not the preferred option of parents, but it may be viewed as the only option:

> As parents, it was clear to us that we secured a diagnosis, medical treatment, educational and social support for Peter by fighting the system, not by engaging with it, as would have been our strongly preferred route (Truss, 2008, p. 372).

There is a view that those parents who 'shout the loudest' get what their children need (Hare et al., 2004), but it can also be argued that unless parents advocate on behalf of their

children, needs might go unmet (Roberts & Whiting, 2011), suggesting that parents may feel that they have to proactive in order for their children's needs to be recognised and addressed. Parents may sense service provision is more dependent upon luck and how hard they fight than on assessment of need (Paradice & Adewusi, 2002). The predisposition parents develop to fight for provision for their children can result in practitioners viewing such parents as problematic, while parents continue to feel they can achieve results for their child by being stubborn (Todd & Jones, 2003). Having developed advocacy skills to support their own child, some parents become activists, fighting not only for the rights of their child but also for other children with special needs (Ryan & Runswick-Cole, 2009).

Hallet and Hallet comment on the current situation in SEN provision:

> It is clear that many parents of pupils with special educational needs and/or disability still have to fight long and hard to achieve the best outcomes for their children. For some, this will be to achieve a place in a specialist setting…for other parents, it is the opposite struggle, to persuade their local authority, or school/setting, to identify and meet the additional needs of their child…There are still too many instances when a pupil, who has been successfully included in the early years of primary education, becomes more and more at odds with classroom practice in the later years, or in secondary school, and is moved to a specialist setting, or excluded… (2011, pp. 110-111).

Struggle and fight metaphors are not restricted to education settings, but also occur in regard to health and other services:

> There was a strong perception among parents that people who 'make a fuss' get more than those who do not. Parents had witnessed disagreements among professionals regarding their child's eligibility and often felt that allocation of services was less driven by need and instead, 'all down to money'. Such views were reinforced by witnessing inequality in provision 'you look at the support that some people get and others don't and in your mind you're thinking, how has that worked?' (Bryson et al., 2008, p. 32).

Not all parents use military metaphors. In a study exploring parental use of metaphors, van Hove et al. (2009) found a range of different metaphors including 'traveller', 'manager', 'trainer/teacher', 'bridge builder', 'tight-rope walker' and 'strategist/diplomat', as well as 'warrior'. Some parents speak of being 'excluded' from decision making about their child (Dempsey et al., 2009).

Furthermore, it is not only parents who use metaphors of struggle and fight. Local authorities and health authorities can also be engaged in a struggle to meet children's needs (Abbott et al., 2001). Parents are fighting for *their* child while the local authority is struggling to meet the needs of *all* children with special needs within the available budget (Batten et al., 2006). In the current economic climate, where budgets and services are subject to cuts, such struggle may be inevitable. Such struggles again reflect the perceived value given to the

expertise of the professional compared with that of the parent, who may be seen as expert in relation to their child but not in relation to appropriate services and provision (Dempsey et al., 2009). This in turn reflects the power structures within the autism spectrum domain and special needs system more generally. As Bendelow and Brady (2002) succinctly express it:

> Clearly, there is a power relationship between a professional and a parent, compounded by the professional's other role as gatekeeper to further important resources. The way in which a child's problem is defined, through the process of assessment and possible diagnosis and treatment, may or may not lead to the needs of the child and parents being met…Parents [of disabled children] have said that it can seem unjust when someone whose involvement is fairly transitory, and may not know the child too well, can have so much of a say (pp. 174-175).

Re-affirming mothers

Much of the literature in the special needs domain and in the autism literature in discussing parents pays little regard to the differing roles of fathers and mothers (Gazeley, 2012; Landeros, 2011), but mothers tend to be more involved with children's school experiences than fathers (Reay, 1998), and in the special needs domain there is some evidence, not only of mothers being most involved in caring roles, but of fathers engaging in activities that remove them from the family setting into work and other activities (Gray, 2003, 2006; Green, 2007; Hastings et al., 2005; Traustadottir, 1991). Not only do mothers carry the heavier care burden, they also tend to be most engaged in discussions with schools and other practitioners (Gazeley, 2012). During the 1960s and 1970s, mothers also carried the burden of blame for their children's autism, due at least in part to the psychogenic theory "that autism developed in infants in response to their aloof and detached 'refrigerator' parents" (Langan, 2011, p. 195), that was popularised by Bettelheim (as cited in Feinstein, 2010 and Silverman, 2012), leading to the stereotype of the 'refrigerator mother' (Silverman, 2012).

Langan (2011) identifies three waves of activism by parents. The first was a reaction against psychogenic theories for the cause of autism. The second, during the 1990s, focused on possible biochemical causes of autism, including reactions to the MMR vaccine and/or thimerosal, and led to the proposal of biochemical treatments and 'cures', including gluten-free/casein-free diets and chelation. The third wave marked a move from viewing autism as a disorder to embracing it as "a different way of thinking and behaving" (Langan, 2011, p. 201), leading to greater collaboration between parents, people with autism, and medical professionals. At the same time some parents have become more vocal in requiring appropriate responses to their children with ASCs. Ryan and Runswick-Cole (2009) discuss the journey undertaken by some mothers towards becoming activists, seeking better support and services for children with autism. Silverman (2012), in her study of the activism of mothers over the past four decades, suggests that far from being cold and unloving, mothers

of children with ASCs demonstrate extreme love, and that love has driven many of the major developments in treatment and understanding of autism over the past four decades.

Sousa (2011) also identifies love as a keystone in the construction of the identity of the 'good mother' and, through an examination of the published memoirs of thirty-three women with children with intellectual disabilities (including autism) shows the metaphor of the 'refrigerator mother' has been largely displaced by that of the 'warrior-hero' who will go to any lengths to ensure her child's needs are addressed. This research focused on women who tended to have a relatively high-status and access to intellectual, cultural, financial and social capital and Sousa suggests "more research is needed on women who fall outside the socioeconomic classes and racial/ethnic categories of the memoir authors" (2011, p. 240). Mothers not only experience tensions in ensuring their children's needs are appropriately met, but they also carry the burden of assumptions made about them as women and the way they might have contributed to their children having an ASC.

Concluding reflections

Problem areas exist within the special needs domain at different levels within the domain. At a structural level, although collaborative and partnership working is endorsed by public policy, in practice there are structural, interprofessional and interpersonal difficulties to overcome. Parent partnership is promoted in the SEN Code of Practice (DFES, 2001), but, in practice, conflict can arise when practitioners fail to recognise the expertise of parents, or parents disagree with decisions made by practitioners. These areas of disagreement are not restricted to any single area or service within the special needs domain, but can occur in relationships with any service and at any level between services.

Practitioners do not necessarily agree with each other. Different professions have different objectives and value systems. Although practitioners may have a common value of seeking what is best for a child with special needs, what they consider best varies according to their professional values and according to the values and objectives of their employing agency. Additionally practitioners are constrained in their actions by public policy.

Parents face their own challenges in parenting a child with special needs, but practitioners are also challenged by shortages of resources and a requirement to address the needs of all children within their area of responsibility. Despite the frequent use of the 'struggle/fight metaphor', there is little evidence of a coherent explanation as to why it is so prevalent. Amongst the factors which may influence the pervasiveness of the metaphor are the difficulties of interagency working (Gray, 1993a), the power relationship between parents and professionals (Daniels et al., 2010; Edwards et al., 2009; Edwards & Kinti, 2010), the adversarial nature of the special needs system (Duncan, 2003; Hodge & Runswick-Cole,

2008; Todd & Higgins, 1998), communication issues (Asthana, 2010; Lamb Inquiry, 2009; Runswick-Cole, 2007b) and failure to recognise parental expertise (Duncan, 2003). Although many of the challenges of parenting a child with special needs are shared by all parents of children who are different from 'typically developing' children, there is some evidence that children with ASCs may present particular challenges.

There is some recent evidence of the appearance of positive metaphors, with the negative imagery of the 'refrigerator mother' being replaced by that of a 'warrior-hero', who not only battles on behalf of her own child, but who works together with practitioners to bring about changes in practice for all children with ASCs.

Most studies in the area of tension and struggle and fight in the special needs domain has tended to focus on specific aspects of the domain. This has been remedied to some extent by the ESRC funded Post-Blair project (Goodley et al., 2011) and the TLRP funded study, 'Learning in and for Interagency Working' (Edwards et al., 2009), but further interconnectivity of thinking is required in order to understand the connections between stresses occurring at different places within the special needs domain, in particular, how the factors shaping the domain influence the experiences of those who work in the domain and the parents of children with special needs, including AS/HFA.

Chapter Five

Methodological Approaches and
Research Design

The chapter is laid out in four sections. Firstly, I recap my research questions and provide a brief outline of my research strategy and how this maps onto the research questions. Secondly, I discuss my positioning within the research process, including how my various identities and the implications of insider research influenced my research design and methodological decisions. Thirdly, I discuss my overall research strategy and detail the research process. Finally, I turn to the process of sense making, or data analysis. Ethical considerations are raised at appropriate places within the discussion and there is also a separate section addressing the ethical principles underpinning the empirical study undertaken as part of this research.

Research Questions

My primary research question: "How and why is the special needs system experienced and viewed as adversarial, despite being established on a foundation of partnership and collaboration?" is addressed through two further questions, focusing on the structure and functionality of the *systems* that comprise the special needs domain, and the experience of stakeholders within the domain. These two perspectives on the problem area, reflect Mills' distinction of 'public issues' and 'personal troubles' (Mills, 1959, p. 10), 'public issues' relating most directly to the public response to special needs while 'personal troubles' relate to the experience of working and/or living with AS/HFA. These two aspects intersect where parents and practitioners interact and where parents seek public solutions to the difficulties their children encounter.

My research strategy considers the structure and functionality of the special needs domain separately from the experience of stakeholders, holding the two approaches together within a whole *systems* approach. I then draw connections between the two approaches. The structure and functionality of the domain is explored firstly through a literature review focusing on the development of the domain and the influences shaping that development and then through the creation of visual models, or diagrams. In order to understand the stakeholder experience, I recruited participants who were parents of children or young people with AS/HFA and practitioners working with children with AS/HFA and their families. Participants were invited to tell their stories of their experiences in the special needs domain, and in particular that part of the domain relating to AS/HFA. I then analysed the stories to identify different aspects of struggle and fight, using the theoretical frameworks discussed in

Chapter Two. The findings from the empirical study were then related to the potential areas of tension emerging from the investigation of the structure and functions of the *system* (Chapter Three) and from my literature searches (Chapter Four).

The self in the research process

At one time the assumption was made that researchers, whatever their methodology, could adopt a neutral and objective stance, such that their personal identity was irrelevant to their work or their findings. This has been challenged by the recognition that no researcher is totally free of their various identities and value system. Mills recognised the problem of bias:

> I am hopeful of course that all my biases will show, for I think judgments should be explicit. But I am also trying, regardless of my own judgments, to state the cultural and political meanings of social science (1959, p. 20).

Later observing:

> The most admirable thinkers within the scholarly community…do not split their work from their lives. They seem to take both too seriously to allow such dissociation, and they want to use each for the enrichment of the other (Mills, 1959, p. 195).

Becker (1967) not only recognised that no sociological research study of the social world is truly value free, but made a powerful case for researchers to declare whose side they were on. This call is reiterated by Frank (1995), who says researchers should identify their standpoint, which is a position that has grown out of their biography and the place where they now find themselves. For Frank taking a standpoint is:

> A political and ethical act of self-reflection…to take a standpoint means to privilege certain aspects of what your biography shares with others (2000, p. 356).

Burgess-Limerick and Burgess-Limerick suggest that not only should researchers identify their standpoint, but should declare:

> Their biographical details, such as substantive interests, philosophical stance, and personal experiences, priorities and values [as these] are important parts of the perspective that the researcher brings to bear on the research (1998, p. 64).

In the Preface to this thesis, I acknowledge my personal interest in the themes explored in this study. It is appropriate to add to this the influence of my professional background in social work and community development. As a newly qualified social worker in the early 1970s, I eschewed a social work model based on psychodynamic theory and personal change (Hollis, 1964; Perlman, 1957) in favour of a community development model that focused on people together gaining access to skills and ownership of resources in order to bring about change in their own lives and more broadly (Calouste Gulbenkian Foundation, 1968, 1973;

Popplestone, 1971). I reasoned that there was little virtue locating a problem in an individual, if nothing was done about wider societal issues that were responsible for the problem emerging. Over the years, I have observed many situations where people have been disempowered through lack of access to information and other resources, and also circumstances where access to knowledge and information has enabled people to take control in extremely difficult situations. As suggested by Truss (2008), I consider the special needs system dysfunctional, but I recognise that before a *system* can be changed it needs to be understood and the potential unintended consequences of any change identified. It is that commitment both to seeing the big picture and to emancipation that leads me to favour *systems* approaches, and particularly those methods that involve stakeholders in the process of bringing about change.

Bourdieu and Wacquant (1992) state that adopting a reflexive perspective is not renouncing objectivity, but rather, by being self-aware, the researcher is able to utilise their thoughts and feelings in their practice. Bourdieu does not directly address the related issue of insider research, but the tension between being a researcher and a practitioner in the field being researched is addressed by a number of authors (for example, Atkinson, 1994; Biott, 1996; Todd, 2000). Ellingson (1998) and Rogers (2003) explore some of the potential problems and advantages of insider research, Ellingson suggesting that as an insider, a researcher is turned into an empathetic listener who shares the feelings and experiences of participants, going on to claim that:

> Although no one can fully understand another's experience, I come closer
> to putting myself in the place of another than one who has never known
> life threatening illness (1998, p. 497).

Similarly, I would claim to have a better understanding of the experience of parenting a child with an ASC than someone who has not had that experience.

There are risks and advantages to undertaking research as an 'insider' (Merrill & West, 2009; Miller & Glassner, 2004; Olesen, 2000; Rogers, 2003). While it can be argued that the 'insider' has a greater understanding of the issues, sharing a lifeworld with participants (Ellingson, 1998; Schutz, 1970), at the same time assumptions can be made about shared meanings and common understanding, resulting in questions not being asked that should be (Rogers, 2003). The researcher's personal knowledge of a domain may enable a fuller understanding of a participant's life experience, but such knowledge may disempower a participant, if it reduces the extent to which they are viewed as an expert about the domain (Miller & Glassner, 2004). Ultimately, whether or not 'insider' research is valid is not about subjectivity, objectivity, or access to otherwise inaccessible data, but about recognising that "utilisation of the self is an essential part of qualitative research" methodology (Olesen, 2000, p. 229).

As an insider within the special needs domain, I also had to decide to what extent my own story would inform the research process. Stanley (1992) has discussed the constructed nature of biography and shown that even in autobiography, it is not only the story of the author that is told, but also the various other lives that have intertwined with and impacted on that of the author. As the mother of a young man with a diagnosis of Asperger's syndrome, I have had to make choices as to how far my story and the experiences of my family form part of my data and are allowed to interact with the stories and experiences of those who have agreed to participate in the study. This has both methodological and ethical implications (Ellis et al., 2011).

When I tell my story, I am also telling my son's story. The identities of other participants and their children can be anonymised, but masking my son's identity is more difficult. Rogers confronted a similar quandary in relation to her daughter:

> There were some occasions where anonymity was impossible: those involving my daughter. I have talked to her about this research and her inclusion (which she agreed to), and I do not apologise for the lack of anonymity here because unlike children in general, many of whom become 'able' adults, she, like many of the participants' children, will never be able to 'tell' her story via this particular medium (2007, p. 17).

In recognising the close link between my story and that of my son, I am aware of my perspective changing as my son has grown into manhood. As a child he was, borrowing the language of activity theory (Daniels et al., 2010), an object that was acted on by others, including me. As a young adult, there are parts of his story that he is happy to share and others that he would prefer to forget. I have respected his views in sharing our story. However it is also necessary to recognise the children of other participants will grow up and may have feelings about the stories that have been shared about their early lives. To protect these 'participants', all identities and locations have been anonymised and only that personal information that is clearly relevant to the topic of this thesis has been included. After much thought and consultation with my son, I decided to include my/his story in this study. Clearly, I was not able to interview myself, but instead I 'told' the story to a recording device, transcribed the recording and included it in the dataset, subjecting it to the same analytical approach as the accounts given by other participants. My account was supported by contemporaneous notes made at the time various incidents had occurred. The decision to include my own case within the dataset enabled incidents to be included that I knew other parents had experienced but which were not included in the narrative accounts of other participants. As with other participants, my account is anonymised.

Research Design

The methodological framework used in this study is based on a whole *system* approach, and the development of *systems* methodologies and thinking is discussed in Chapter Two. Such an approach utilises a variety of techniques and theoretical perspectives, as appropriate to the problem area being investigated, in order to view the problem area holistically and to gain a richer picture, or understanding, of the whole *system*, including the interconnectivity of the different aspects of the *system*. Although, *systems* approaches, especially in engineering sciences, can be viewed as positivist, soft systems approaches that recognise the human contribution to the operation of a *system* and lay emphasis on both the perspective of each agent, representing their viewpoint at that time and under the given circumstances, and the worldview of each agent (Weltanschauung), representing the individual's fundamental values and dispositions (Checkland, 1999, 2000). *Systems* approaches also recognise that any investigation is at best partial. Detailed exploration of specific aspects of the problem area is not precluded, but is undertaken in the context of the interconnected nature of the whole *system*.

Whole *system* approaches can be used both to understand a problem area, or *system* of interest, and as part of a change process, where the potential for unintended consequences resulting from proposed changes can be identified, and strategies put in place to avoid or ameliorate them (Checkland & Poulter, 2010). Whole *system* approaches are particularly appropriate in the context of large, complex, interconnected *systems* (Jackson, 2000, 2006), such as that represented by the special needs domain.

Complex *systems* have been described as "often only partially observable, probabilistic, open, have purposeful parts and are subject to behavioural influences" (Jackson & Keys, 1984, p. 476). In this study, the whole *system* is the special needs domain. The problem area under consideration is that of why the special needs domain is considered adversarial and a site of tension as viewed from the perspective those who work with or parent children with AS/HFA. I use two approaches to explore the problem area. The first centres on understanding the domain in its wider socio-political-legal context and determining its boundary and structure. This is addressed through a literature review and use of diagramming techniques to create visual models and forms the basis of Chapter Three of this thesis. The second part of the investigation focuses on the experience of struggle and fight of parents of children with AS/HFA and practitioners working in the domain and is the focus of Chapters Six to Eight.

As discussed in Chapter Four, much research in the special needs domain focuses on specific aspects of the domain. Focusing on detail may obscure the bigger picture. *Systems* approaches enable a more holistic exploration of problem areas, without necessarily claiming

to have a view of all aspects of the *system*. Todd, in commending an activity system approach, wrote:

> We cannot understand what kinds of partnerships between children, young people, parents and professionals are needed to develop inclusive education without taking into consideration the history of the development of relationships between families and schools…An activity system puts human activity into the social, political, historical and economic context in which it occurs (2007, p. 16).

A whole *system* approach similarly promotes understanding of the structure, context and historical development of the special needs domain, and enables the 'struggle/fight metaphor' to be understood socially and contextually. Although a research approach focusing only on the lived experience of the 'struggle/fight metaphor', or only on the structure, function and interconnectivity of the *system*, would be informative and would not necessarily ignore other aspects of the domain, taken together the approaches provide a richer picture of tension within the domain.

The approach used in this study is based on a model developed by The Open University Systems Practice Group (The Open University, 2003) and used extensively in Open University modules and workshops to enable participants to draw on approaches drawn from different *systems* methodologies as relevant to the context and the *system* being explored. This model was introduced in Chapter Two and is known as the SUDA approach because of its four phases of enquiry, namely Sensing, Understanding, Deciding and Acting (Figure 4).
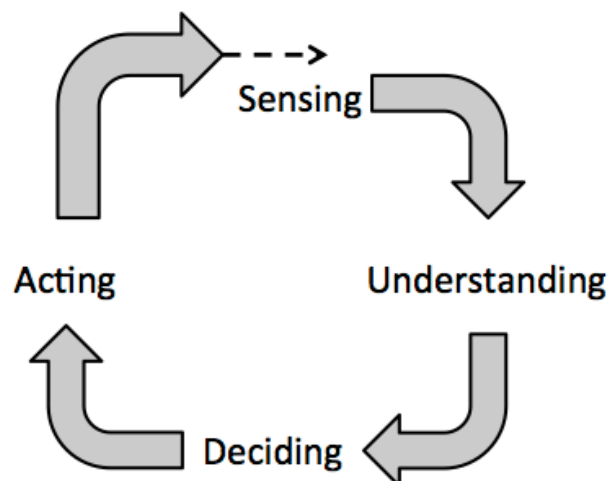
Figure 4 Four phase cycle of enquiry ©The Open University (The Open University, 2003, p. 5)

My investigation was an iterative process, consisting of four phases, each of which are outlined here and then discussed in more detail:

The first stage, as represented in the **sensing** phase of the SUDA model, focuses on contextualising the setting. This involved exploring the historic development of the special needs domain and the factors that had influenced and shaped it, together with understanding what is currently known about the nature of the 'struggle/fight metaphor' within the special needs domain. The output of this stage of the inquiry is found in Chapters Three and Four of this thesis.

The second stage was a continuation of the **sensing** phase of the SUDA model, but moved into **understanding**. I developed a series of visual models, or diagrams, representing the domain from different perspectives. The diagrams served two functions, providing both a visual representation of the domain, including its boundaries, and indicating areas of potential tension within the domain, some of which were also evident from the literature reviews of stage one. These themes were returned to in the third and fourth stages. The output from this stage of the inquiry is found in the diagrams introducing Chapter Three and in Appendix A.

The third stage focused on **understanding** the experiences of parents and practitioners in the special needs domain. It involved narrative interviews in which participants shared their stories. Throughout the investigation, I was also monitoring parent-led online forums and facilitating a parent support group. Although these latter activities were not used as a source of data, they did enrich my own understanding of the problem area from the parental perspective. The output from this stage of the inquiry is found in Chapters Six, Seven and Eight.

The fourth stage of the investigation was the analysis stage, which involved making sense of the data and presenting it in an accessible form. These activities map on to the **deciding** and **acting** phases of the SUDA model. The output of this stage in the inquiry is also found in Chapters Six, Seven and Eight.

The SUDA model can be considered a mixed methods approach in that it encourages the use of a range of approaches to understanding a problem area. Depending upon the nature of the investigation, this can include both quantitative and qualitative methodologies and techniques. Traditionally, the term 'mixed methods' has been reserved for the use of quantitative and qualitative approaches within a single study, but Creswell (2009) argues this understanding should be reviewed and other combinations of methodologies should also be considered mixed methods, reflecting the views of Mason (2006), Kral et al. (2011), Quinlan and Quinlan (2010) and Russell et al. (2012). Kral et al. (2011) call for the adoption of multiple perspectives, interdisciplinary conversation and multidimensional approaches and

Mason (2006) argues for the combination of different qualitative approaches within a single study in those studies based on qualitative methods in order to ensure social science research methods fully recognise the multidimensional reality of human experience. A *systems* approach not only permits but expects the practitioner to use a number of different techniques within a single investigation (Reynolds & Holwell, 2010).

Stage One – literature reviews - Sensing

The first stage of the investigation was a literature search, focusing initially on identifying literature relating to the special needs domain as a *system*. This led me to an article arguing for a reconceptualisation of the SEN system using whole *systems* approaches (Truss, 2008). Following the references in this article led to a number of other texts, including some based on the *systems* models developed by Bronfenbrenner (Bronfenbrenner, 1977, 1986; Leonard, 2011; Newbury, 2011; Russell, 2003; Swick & Williams, 2006).

I then turned to the 'struggle/fight metaphor' and used keyword searches in a number of databases. I found that using the words 'struggle' or 'fight' in a search took me to results which discussed behaviour management, but did not lead me to material exploring the adversarial nature of the special needs domain. However, I was now identifying a number of authors who were writing about different aspects of the special needs domain, or about autism. I was able to use the references and bibliographies in their work to learn more of the background to the special needs domain. In many instances, the journal websites also offered lists indicating where this work had been cited and allowed me to set up citation alerts to capture additional, more recent citations.

A further avenue of exploration was the development of the SEN system, which led me to more recent government reports concerning the problematic nature of the system, and these in turn led to further literature.

Somewhat serendipitously, I became aware of the TLRP funded study, 'Learning in and for Interagency Working' (Edwards et al., 2009), which, while not focusing on special needs, identified interagency working as an area of stress in addressing the needs of troubled children, thus providing another area for exploration.

Although this was not a systematic literature search, once I had identified key search terms, authors, journals and other sources of information, I was able to set up electronic alerts to ensure I kept abreast of more recent publications. I was aided further by the publication of the SEN Green Paper (DfE, 2011), with an extensive bibliography, containing links to many studies undertaken during the preparation of the consultation document.

The literature search was ongoing throughout the research.

Stage Two – mapping the domain - Sensing and Understanding

The main focus of this stage of the investigation was mapping the domain. During the literature searches of Stage One, I looked for visual representations of the domain and was surprised to find only one representation, which is reproduced as Figure 5 (Truss, 2008, p. 373). This diagram appeared to have a number of shortcomings and omissions, leading me to create a spray diagram, included in Appendix A, based on my knowledge of the domain from personal experience as a parent and support group facilitator and previous knowledge gained from working in local authorities. The spray diagram provided a starting point for a number of informal, exploratory discussions with practitioners and parents familiar with the domain, including members of the parent support group I facilitate and practitioners known to me personally. These discussions enabled me to identify more clearly the main features and divisions of the domain, and to recognise elements that were missing from the diagram. I was able to discuss my diagramming with Katie Truss, the originator of Figure 5, and to clarify that she had undertaken a similar process in arriving at her diagram, recognising the need for clarity that was not present in a spray diagram.

Following these discussions, I created further diagrams, which I placed on a wiki[7], together with explanatory comments, and invited comments from colleagues at Sussex, colleagues involved in designing and teaching modules focusing on special needs at the Open University, and staff and students with a special interest in autism at another university. The comments received from these sources, led to further iterations of the diagrams. Although most of the diagrams do not form part of the body of this thesis, the understanding gained from them underpins my understanding of the structure and functionality of the domain, and led to the creation of other diagrams, which are used in the body of the thesis.

Mapping the special needs domain not only provided visual representations of the area being studied, but enabled me to consider the domain both as a *system*, with a purpose, comprised of many interconnected *systems*, each with a purpose, and also, using a Bourdieusian perspective, to view the domain as a *field* structure, comprising a number of independent *fields* of struggle, each occupied by social agents. Viewing the domain as a *system* enabled the identification of features of the *system* that contributed to tension within the domain. Some of these features were present in the initial literature survey of Stage One, while others led to further literature searches. Similarly, recognising the *field* structure enabled me to focus on the activity and struggle within each *field*, again leading to reflection on the literature, in particular that relating to the capital resources and attributes of social agents, and laying the foundations for the next stages of the investigation.

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[7] A wiki is a website that facilitates editing and commenting by visitors to the site. My wiki can be viewed at http://lizit.pbworks.com/w/page/33034112/Diagramming%20the%20autistic%20spectrum%20domain%20systems Unfortunately, due to a requirement for visitors to register on the site before being able to comment, the wiki did not work as intended, but I was able to elicit email feedback on the diagrams.
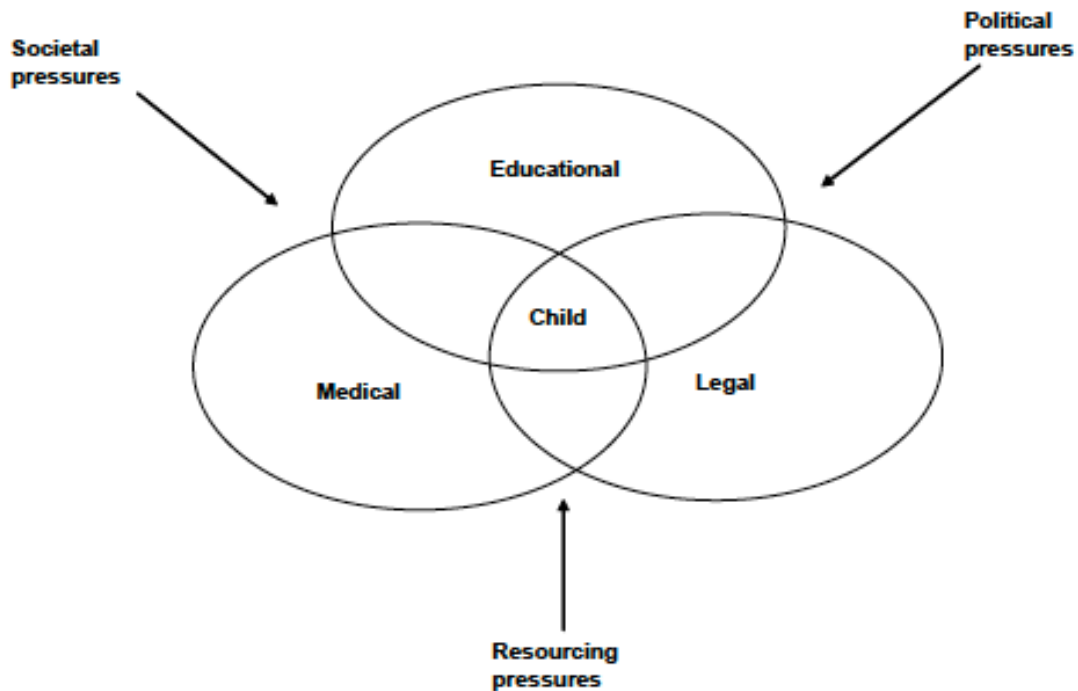
Figure 5 The three domains of the SEN system (Truss, 2008 p.273), used
by permission © Taylor and Francis Group http://www.tandfonline.com

Stage Three – narrative inquiry - Understanding

This stage of the investigation represented a move from modelling, which is quasi-objective, to the use of narrative inquiry methods to collect stories of the personal experiences of parents and practitioners within the special needs domain. This is a qualitative research approach, and before describing this aspect of the study in more detail, I discuss why this was viewed as the most appropriate approach for this phase of the study.

Qualitative research approaches

Research methods can be divided into two broad areas, those designed to test hypotheses using quantifiable data, and those designed to understand a problem area or phenomenon. As discussed above, *systems* approaches encourage the use of a variety of methods, including the use of quantifiable and qualitative data and modelling techniques. Whereas quantitative studies address questions about 'how much' or 'how many' (Green & Thorogood, 2004), qualitative studies set out to answer questions about 'what', 'how' or 'why' and allow people a voice from which aspects of theory can emerge (Glaser & Strauss, 1967). *Systems* approaches are concerned with 'what', 'how' and 'why' questions, but also explore interconnectivity, influences and outcomes, in order to engage in problem solving, through

identifying causation and investigating the effects of change, actual or potential. Central to *systems* thinking is an awareness of the need to devise methods for understanding complex, contradictory and messy human systems. Mason asks:

> How is it possible to reconcile different epistemologies and ontologies which may result in vastly differing world views and may depend upon contrasting explanatory logics? How can we integrate different forms of data and knowledge? (2006, p. 19).

I suggest *systems* approaches offer a partial answer.

The purpose of this stage of the investigation was to give a voice to people with experience of the special needs domain. It was not about objectivity and quantification, but about what it feels like to work in, or use the services of, a domain that is described as adversarial (DfE, 2011, p. 15, para 7).

In the past, qualitative research has been regarded with a degree of suspicion by those researchers adhering to a positivist tradition. Although the so-called 'paradigm wars' are now largely a thing of the past, there is a continuing tendency to seek to validate qualitative research with measures more appropriate to quantitative research (Maxwell, 2010; Merriam, 1995) and to develop methodological approaches that meet quantitative standards of consistency and replication. Many *systems* methodologies have their roots in the engineering sciences and these approaches tend to be prefixed by the word 'hard' denoting both their origins and the quantifiable nature of the approach. However, as discussed in Chapter Two, such approaches were found inappropriate in situations where complexity was rooted not only in the structure and mechanics of the *system*, but in human relationships and how people related to the *system* and to each other. This led to a second wave of *systems* methodologies and approaches, referred to generically as soft *systems*.

Central to the quantitative/qualitative debate are questions of how to judge the validity, reliability and generalisability of research findings. Maxwell (2010) suggests this is not the appropriate question to ask, as qualitative and quantitative methodologies are not only different approaches to research, but they represent different mindsets. According to Mohr (as cited in Maxwell, 2010) those research methods using quantitative measurement, statistical analysis and controlled experiments represent a 'variance theory' mindset, whereas methods that focus on understanding and explaining the relationships between events and processes represent 'process theory'. Thomas (2010) discusses the problem of validity in relation to narrative methods, referring to what she describes as an "ongoing debate", stemming from Atkinson's (1997) suggestion, that personal stories and narratives were being privileged inappropriately over more objective data sources. Thomas (2010), writing in the field of the sociology of health and illness, distinguishes the objective medical account, which can be viewed as 'variance theory', from the patient experience, representing 'process

theory', and suggests both approaches are authentic and valid, rather than that one approach being more valid than the other. *Systems* methods, in combining many different approaches, include both variance and process perspectives. Soft systems methodologies, in particular, foreground the understanding of *systems* from a human, or stakeholder perspective. A narrative inquiry approach is not only a qualitative methodology, but appropriate for understanding the experiences of participants of the special needs domain.

Stakeholder perspectives – narrative inquiry

Ascertaining stakeholder perspectives is an essential part of any *systems* investigation. Stakeholders are those people who have a vested interest in the *system*. That interest may have many different sources including consuming or using resources provided by the *system*; financing the *system*, through the taxation system or through ownership of a share of the system; and working for the system in order to earn a living. Stakeholders are not only those directly involved with, or influenced by the *system*, but may include members of the general public who are affected in other ways by the *system*. For example, parents of typically developing children may perceive their children as disadvantaged, if they share a classroom with children with special needs whose needs they consider are not appropriately addressed, resulting in disruption to the education of all the children in the class[8].

Stakeholder perspectives can be explored in a range of different ways. In this study, I used biographical methods to collect stories told by individuals of their experience of the special needs domain and limited the scope of the study to those working with or parenting children with AS/HFA. Throughout the study, I was embedded in the domain as I continued to facilitate a parent support group and participate in online forums. This ensured I was aware of developing issues within the special needs domain, especially during the latter stages of the study when analysing data and writing. As discussed in the Ethics section of this chapter, these groups were also used in a very limited way to recruit some participants, but they were not used as a data source. Consideration was given to the use of diary studies but this proved impossible to organise. Use was made of the extensive notes and copies of correspondence that were made available by one participant, which recorded contact with practitioners during the time she was negotiating a school placement for her son. In addition to the stakeholders included in the interview sample, I engaged in email correspondence with the parent of another child with AS/HFA, who was aware of this study and who offered me permission to use material from our correspondence – an offer I accepted.

Biographical and narrative methods are long established in the social sciences. The earliest generally acknowledged sociological study based on narrative is Thomas and Znaniecki's

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[8] This is an issue that attracts media attention from time to time, but research studies suggest that the problem is exaggerated (Dyson et al., 2004, pp. 79-83; Farrell et al., 2007).

study of Polish immigrants to the United States in the early part of the twentieth century (Thomas & Znaniecki, 1958 [first published 1918-1921], as cited in Merrill & West, 2009), but an interest in people's personal stories and accounts pre-dates this work, with many earlier accounts of social life as found in the well known works of Mayhew and Pepys and lesser known works, such as a collection of articles originally printed in the Manchester Examiner and Times, chronicling the experience of cotton workers in the mid-nineteenth century (Waugh, undated). The 1920s saw the birth of the Chicago School of Sociology, which continued to be influential into the 1960s, placing an emphasis on case study methods using participant observation, personal documents and auto/biographical writing. During the 1950s and 60s, many texts were published in this tradition, which used ethnographic methods to investigate life experiences. These include Young and Willmott's study of life in the East End of London (1957) and the subsequent move to suburbia (1960), Townsend's study of the family life of old people (1957), Hoggart's "The Uses of Literacy" (1957) and Jackson and Marsden's semi-autobiographical account of education and the working classes (1966). It appears that the 1970s saw a shift to favouring research methodologies that presented 'hard' facts (Gherardi & Turner, 2002; Maxwell, 2002), preceding a narrative turn (Merrill & West, 2009; Riessman, 2008).

By the 1990s, story telling and other narrative approaches were again a recognised and accepted part of the sociological cannon, but the methodology continues to be subject to some discussion and challenge (Atkinson, 1997; Bochner, 2001; Silverman, 2004; Thomas, 2010). Of interest within the context of this study is the further dimension of the perspective from which a life story is told. Stanley (1992, 1993) makes a significant contribution to this discussion in clarifying that all biographies are filtered and constructed versions of reality, in which an author, in telling their own story, also tells the stories of others, but chooses which aspects of the story to tell and what values to impose on the story. In the area of special needs, it can be anticipated that the story told by a parent will be different from that told by a practitioner, and that the story told by a practitioner will depend on their area of expertise and their positioning within that area. In a health context, Mishler (1984) differentiates the medical and lifeworld[9] voices present in medical consultations, where there is little space for the lifeworld voice of the patient to be heard unless the clinician makes space for the patient to tell their own story (Clark & Mishler, 1992). Practitioners may be unaware that there is a story to tell, and that there is a difference between taking a medical history and hearing a person's story (Frank, 1995). In the lifeworld of children with AS/HFA there are many competing voices, only one of which is the voice of medicine (Coyle, 1999). Although this study does not provide space for all those voices, my aim in sampling and selecting

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[9] Husserl developed the concept of lifeworld to mean "the whole sphere of everyday experiences, orientations, and actions through which individuals pursue their interests and affairs by manipulating objects, dealing with people, conceiving plans, and carrying them out" (Wagner writing in Schutz, 1970, pp. 14-15) and was later developed by Schutz as part of his phenomenology Schutz (1970).

stakeholders was to hear and collect a range of different stories from a wide range of different perspectives, representing a breadth of experience, and giving expression to voices that might not otherwise be heard (Becker, 1967).

Selection of participants

The list of potential stakeholders that could be included in this study is potentially limitless. The special needs domain contains the competing voices of educationalists, psychologists, medical practitioners, politicians, social workers, parents of children with and without special needs and the general public, not forgetting the voice of the person at the centre of the domain, who is deemed to have special needs, be they child, young person or adult. Some of these voices are well documented, as discussed in Chapter Four, but others are less heard or differently heard. As this was a limited study, the sample did not include representatives of all stakeholder groups, but was limited to those most intimately involved in the special needs domain as it applies to children and young people with AS/HFA, namely parents, health service practitioners, teachers and education support staff (see Table 1). The sample did not include social care practitioners as relatively few families with children with AS/HFA are supported by children's services (Goodley & Runswick-Cole, 2011). Also absent from the sample are local authority decision makers and representatives of voluntary organisations and community groups, though a number of the practitioners had sat on local authority decision making panels and were cognisant with the decision making process. My approach to sampling was a combination of convenience, opportunity, and purposive approaches.

A more notable group of absentees from the sample are the children and young people with AS/HFA who are arguably the principal stakeholders in a study focusing on the 'struggle/fight metaphor' in the special needs system. Todd (2007) discusses at some length the formal structures surrounding SEN, which place an emphasis on ascertaining the views of the child, but exclude the child from meetings in which decisions are made about their future. She cites the findings of Thomas and O'Kane, who found:

> Children were less likely to be involved in meetings if 'big' decisions had to be made or if there was conflict between the local authority and their families (1999, as cited in Todd, 2007, p. 48).

This study focuses on the 'struggle/fight metaphor' within the special needs system as experienced by parents and practitioners rather than the experience of individuals with special needs. These tensions affect children and young people, but I consider their experiences of struggle and fight would be the focus of a different study. Further, children and young people with AS/HFA are considered vulnerable both on the grounds of age and also because of their 'disability'. Neither of these factors are reasons to silence children and young people, but inviting their participation in a study such as this could in some cases exacerbate an already difficult family relationship or result in other problems. As I am not

equipped to provide an appropriate support framework, I am of the view that an investigation involving children should be set up with appropriate management and resources to address any consequential effect on participants.

Recruitment of participants

Participants were recruited because they worked with and/or parented children or young people with AS/HFA and not because they were known to have experienced any problems or difficulties within the special needs domain.

I initially approached the SENCo of a mainstream infant school, the principal of a specialist residential school and a community paediatrician, all of whom I had had prior contact with, to explain the purpose of my research and to ask if they could facilitate access to staff with experience of AS/HFA and/or parents of children or young people with AS/HFA. The initial purpose of the research study was an exploration of the learning journeys of parents and practitioners (see Appendix C), but following initial data analysis, the struggle/fight metaphor emerged as a major theme and became the focus of the study. Both schools gave access to members of teaching and support staff. In addition, the SENCo at the infant school agreed to contact, on my behalf, a number of parents whose children were no longer at the school, asking if they would be willing to be interviewed. The community paediatrician offered to facilitate contact with members of his team, but, due to staffing changes during the data collection period, it was necessary to recruit other health staff from elsewhere. This was achieved through an online support group, which I have been a member of for some years, and through other social network contacts.

I have regular contact with several parents of children with AS/HFA through the support group I facilitate and other personal contacts. Although many of these parents met the study criteria of having a child with AS/HFA, I did not recruit participants from these sources, except when there was a compelling reason to do so, and when the parent was no longer an active member of the support group. Although issues discussed in the support group are frequently relevant to the themes discussed in this thesis, I refrained from making use of material emerging in these group discussions, both on ethical grounds, as I had no permission from group members to use their contributions in this way, and because of the need to differentiate my identity as researcher from that of support group facilitator.

The twelve parents participating in the study were all females and, apart from one girl, their children with AS/HFA were boys. As discussed in Chapter Four, there is a tendency in families with a child with AS/HFA for mothers to be the primary carer. During the study period, I was in contact with one man who was the primary carer for his son with AS/HFA, but I decided not to approach him to participate in this study as he was an active participant in the support group I facilitated, and as already explained, I excluded members of this group from the

sample. I did not attempt to recruit other fathers to the study as I was not investigating the differing experiences of parents of different genders. As discussed in Chapter Three, far more boys than girls are diagnosed with AS/HFA. Although I specifically recruited the parent of the one girl included in the study, this was on the basis of what I knew of her experiences, which I wanted to see reflected in the data, and not because she had a daughter. Other researchers in this area may regard the gender of parents and children as significant in sampling. Similarly other researchers may wish to consider the impact on parents of having more than one child with special needs.

The practitioners participating in the study (see Table 1) were all aware that they were being interviewed as individuals because of their domain knowledge, and not as representatives of their employing organisation or profession. All participants were given both a pseudonym (where possible chosen by the participant) and a reference number. The names and locations of all schools and other organisations are disguised.

The interviews

The interviews were undertaken during a thirteen month period between April 2010 and May 2011, with the majority of the interviews taking place in the six months between April and September 2010. Interviews took place in a variety of settings including practitioners' workplaces, my living room, an office on campus, and participants' homes. Two of the interviews with practitioners used Internet technology. Interview locations were selected on the basis of convenience to the participant, minimal risk of disturbance and a reasonable level of comfort. Interviews varied in length from 40 minutes to approaching 2 hours, with most lasting about 90 minutes.

Each participant was interviewed once. Prior to each interview, I sent each participant a copy of the information sheet (Appendix C) and the consent form (Appendix D) and, at the start of each interview, I gave each participant further copies of these documents, ensured the participant knew that they had a right to withdraw from the research, and checked that they understood that the interview would be recorded and that they were agreeable to this. I also explained the format of the interview to participants, clarifying that I would not be using a list of prepared questions, but that I would guide the conversation in order to ensure the areas I wanted to cover had been discussed. This approach of a guided conversation follows the model suggested by Burgess (1984, 1988) for semi-structured interviews. While setting up my equipment, I also asked participants to complete a form providing background information about themselves (Appendix E). Space was provided at the start and close of the interview for participants to ask any questions they might have about the study.

When it was clear that the participant understood the context and structure of the interview, I invited them to tell their own story of how they had learned about 'what we call autism' and

Name	Ref. No.	Role
Sonia	Pr-01	Head of specialist residential school
Jim	Pr-02	Learning Support Assistant (LSA) specialist residential school
Ruth	Pr-03	LSA specialist residential school
Pam	Pr-04	Teacher specialist residential school
Mike	Pr-05	Teacher specialist residential school
Kate	Pr-06	Teacher in mainstream school
Louise	Pr-07	LSA mainstream school
Mary	Pr-08	SENCo – mainstream school
Sue	Pr-09	LSA mainstream school
Kerry	Pr-10	Teacher at local authority specialist day school
Joan	Pr-11	Educational Psychologist in Home Counties
Chris	Pr-12	Medical student on community paediatric placement
John	Pr-13	Consultant Community Paediatrician
Sarah	Pr-14	Clinical psychologist in Home Counties
Brenda	Pr-15	Retired specialist Speech and Language Therapist (SLT)
Jenny	P-01	Parent – son (11 years) with AS/ADHD/ODD at residential school
Jane	P-02	Parent – adult son (22 years) with AS
Angela	P-03	Parent – son (8 years) with AS in mainstream school
Carol	P-04	Parent – son (8 years) with HFA in mainstream school
Sally	P-05	Parent – son (10 years) with AS in mainstream school
Paula	P-06	Parent (also LSA) – son (10 years) with ADHD and autism in mainstream school
Naomi	P-07	Parent – son (12 years) with AS and Tourettes in mainstream school
Penny	P-08	Parent and professional carer – son (7 years) showing autistic traits
Linda	P-09	Parent – son (13 years) with ASC at residential specialist school
Lynn	P-10	Parent – son (18 years) with AS, ADHD and dyslexia at FE college, formerly attended residential specialist school
Susanne	P-11	Parent (also LSA) – daughter (12 years) with ASC and epilepsy in local authority special school
Janet	P-12	Parent – son (10 years) with AS in mainstream school

Table 1 List of stakeholders participating in study - all names are pseudonyms

the support structures for families with children on the autism spectrum. During this account, which varied from a few minutes to nearly an hour, I engaged in active listening[10], that is encouraging participants to continue their story through being attentive, and sometimes asking questions in the form of reflecting back words or ideas they had already expressed. In general, participants needed little encouragement to tell their stories, but where encouragement was needed, I asked about critical incidents (Flanagan, 1954).

Critical incidents, as defined by Flanagan, are events that take place in a relatively short period of time, and critical incident methodology was initially developed to obtain information from service personnel involved in accidents and near-misses during the Second World War, but it has since been used in a variety of situations, including business, health and education settings (Angelides & Ainscow, 2000; Branch et al., 1993; Cope & Watts, 2000; Howitt & Venville, 2009; Macfarlane, 2003; Woods, 1993). Some critical events may take place over a longer period of time as in the 'event' known as retirement (Hodkinson, 2010; Hodkinson et al., 2008), where there may be a lengthy period of retirement preparation followed by a period of enjoying retirement before moving into a further period of advanced aging with decreasing ability. A similar process is observable amongst parents of children with AS/HFA, where there can be a period of knowing or suspecting something is different about a child, which may be confirmed at a particular time through a formal diagnosis, but is followed by a period of acceptance of the diagnosis and learning what it means for the child and the family. Flanagan observed that individuals were able to recall detailed information about critical incidents some considerable time after the event itself had occurred and Smith and Daughtrey (2000) note that the details of a first diagnosis can remain with parents for a considerable period of time, some parents being able to recall many years later the exact words practitioners used at the time of the diagnosis.

I did not use pre-scripted questions or prompts, but had an interview schedule listing areas and themes that I hoped to explore during the interview. A copy of my interview planning and outline schedule is in Appendix F. This approach permitted flexibility in the structure and format of the interview. For parents, the areas for exploration included how they had become aware of their child's autism, the diagnostic process, school experience, the effect on the family, access to support including disability living allowance (DLA), and sources of information and advice. For practitioners, areas for exploration included their journey to their current occupation, how and where they had learned about autism, their knowledge of the special needs system and their experience of partnership and collaborative working. Most of these areas, and others, arose spontaneously during the interview. In practice, participants needed few prompts, and, as has been reported by other researchers using similar

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[10] Active listening is a technique frequently used in therapeutic interviews and I have received training in this approach during my career in social work and through counselling training. It is adaptable to most other interview situations.

approaches, the interviews tended to be conversational rather than formal (Burgess, 1988; Clandinin & Connelly, 2000; Wynne, 1988).

Towards the end of each interview, I asked participants if there was anything else they felt that I should have asked them, which in some instances led to further areas being explored. At the end of the interview, I told participants that the next stage in the process would be for me to transcribe the interview and prepare a summary and to send them copies of both documents to check and make any corrections or additions. I also reminded them that I would let them have a summary of the research findings after the study was completed.

In determining the structure of the interview, I consulted a number of texts (Kvale & Brinkmann, 2009; Merrill & West, 2009; Silverman, 2001). Some emphasised the value of conversational interviews (Burgess-Limerick & Burgess-Limerick, 1998) while others regarded a structured approach as most desirable, where possible presenting participants with stimuli that were as similar as possible for each participant (Atkinson, 1997; Silverman, 2001). Others questioned the extent to which a truly objective approach is achievable in practice, given each interview is an encounter between two individuals (Mishler, 1986). I was most influenced by the advice of Merrill and West (2009) to experiment with different approaches and methodologies in order to find one appropriate to the study being undertaken, rather than seeking to emulate another practitioner or to adopt a specific methodology. In this study, that meant recognising that an interview is the joint construction of the interviewer and participant, and the skill of the interviewer lies in enabling the participant to find their own voice and tell their own story.

Ethical considerations

I was guided in my research by the British Sociological Association's ethical guidelines (BSA, 2002/2004) and ethical approval for the part of study that involved obtaining stakeholder perspectives was obtained from the University of Sussex SciTech Research Governance Committee (Reference number: SRG/04/05/50). The original focus of my research was the learning journeys of those involved in providing care and support to children and young people on the autistic spectrum, which was later refined to focus on the 'struggle/fight metaphor' within the broader special needs domain, but restricted to the experiences of parents of children with AS/HFA and practitioners working with children and families with AS/HFA. I was concerned as to whether my ethics approval was still valid following these changes, but, after consulting my supervisors and the University Research Governance Officer, I was reassured that as my methodology was unaltered, this did not present a problem.

In my application for ethical approval, I made it clear that, although I would not be interviewing 'vulnerable' individuals, the interviews might be stressful for some participants in recalling private, personal and troublesome events. Participants were made aware that they were free to withdraw from the interview and the study at any time and that they could request a break during the interview if they wished. In my role, as facilitator of a support group for parents of children with special needs, I am used to talking with parents who are distressed and I am familiar with the various support services available to parents should they wish to seek support and advice. I have a social work background and some counselling training, which also equips me to recognise and respond to distress.

During the study, other ethical issues became evident, especially those concerning aspects of confidentiality and anonymity. Although all participants were given a reference code and names and places were anonymised, I was aware that several of the participants came from the same locality and knew each other in a variety of different contexts. Several had children at the same school and were members of the same social networks. Many of the children had been diagnosed through the same NHS Child Development Team (CDT). There were occasions in the interview context when a participant would refer to another participant by name. In the case of references to practitioners, this generally related to their role, but in the case of parents speaking of other parents, this could include relating something of the experience of the other. As I knew that some of the parents knew each other, met each other regularly, and had probably discussed the interview, I was careful not to encourage these disclosures, but accepted that it would be unrealistic to expect them not to occur.

Knowing that information was being shared between participants laid an additional layer of responsibility on me as the researcher to maintain confidentiality, especially when a direct reference was made by a third party to something discussed in an interview with a research participant. An example of such an exchange was a discussion during one interview relating to anxiety about the teen years. Shortly afterwards, I was contacted by another parent, who I have known for several years and who is joint facilitator of a parent support group with the study participant. She invited me to speak about my experience of my son's teen years at the parent group, the participant in my study having suggested this to her. I felt able to accept this invitation, as, although the topic had been raised in the context of the interview, I am the mother of a young man with a diagnosis of AS/HFA, I share my personal experiences freely in the support group that I facilitate, and the topic was one of interest to parents of children approaching their teens. I did not view the request as prejudicial to either of my roles, but if I had judged there was a risk of confidences being broken, my response would have been different. However, this does highlight the reality that not only did I have multiple identities, as discussed earlier in this chapter, but that the same was true for the participants in my study.

Merrill and West (2009) discuss the extent to which it is possible to disguise the identities of people, especially where sensitive material is being shared and recognise that although a number of identifying factors can be changed, it is not possible to hide a participant's identity completely from those who know that person well. Although it is unlikely participants in this study would be identifiable by strangers, it is likely that they will not only recognise themselves, but may recognise others well known to them. This placed a particular responsibility on me not to include details of events or circumstances that should remain confidential, while at the same time providing opportunities for the voices of participants to be heard in writing the findings and discussion chapters in this thesis and in other contexts where I am disseminating information.

An early decision concerned the relationship between my research activity and my involvement in the domain through facilitating a support group for parents with children with special needs. Although many of the parents attending the group have children with a diagnosis of AS/HFA, and most are aware of my identity as a research student as well as a parent, I made the decision at the start of my research that it was inappropriate, even with the permission of group members, to use content from interactions within the group as a data source. At times, I was sorely tempted to review this decision as many group conversations were highly pertinent to my research questions, but, apart from confusing my role within the group, it would have been an abuse of my access to privileged and confidential information. If I had chosen to use this privileged knowledge without permission, I would have been in contravention of the BSA ethical code on grounds of covert observation and deception. If I had permission to observe and use material discussed in confidential meetings, this could have had consequences for the group interaction more generally, as shown by Mickelson's (1997) reflections on her study of an online parent support forum, which almost led to the group ceasing to function. As far as possible, I have sought to keep my research activity separate from my involvement in this group, but it is impossible to unpick which elements of my own understanding of the autism spectrum domain emanate from my involvement in this group, which are based on my personal experience, which stem from my reading and research activities and which have their roots elsewhere.

Stage 4 - Data analysis – Deciding and Acting

The main dataset requiring analysis was the narrative data from the stakeholder interviews, but there was also data to be considered from the outputs of the visual modelling that I did and the earlier work undertaken in sensing the influences on the special needs domain during its development. This section focuses on the qualitative, thematic analysis of the narrative data. Thematic analysis lays "emphasis on what is said rather than how it is said" (Bryman, 2008, p. 553).

The narrative data were used to explore how people involved with the special needs system experience the system, and to differentiate the different aspects of struggle and fight, recognising the distinction between 'personal trouble' and 'public issues' (Mills, 1959, p. 10). Data analysis focused on the content of the narratives, rather than how participants had constructed their stories. In approaching the data, I experienced a tension between ensuring proper respect was paid to the interview participants and their stories and subjecting the transcripts to a level of fragmentation in order to elucidate themes, that might lead to a loss of context (Bryman, 2008, p. 553) and the sequential and structural features of the narrative accounts being removed (Riessman, 2002). Traditional approaches to analysis can lead to the stories people tell being fractured and I was attracted more by the holistic approaches described by Merrill and West (2009), which sought to understand not only the content of the participant's story, but the psychodynamic and socio-cultural elements underpinning who the person is. The narrative inquiry approach described by Clandinin and Connelly resonated with me in terms of its underlying values:

> In our work, we keep in the foreground of our writing a narrative view of experience, with the participants' and researchers' narratives of experience situated and lived out on storied landscapes as our theoretical methodological frame (2000, p. 128).

Although at a personal level I was resistant to hiding the very real emotions that form an essential part of people's stories behind a neat framework of themes and coding schemes, I realised that a framework was necessary in order to make sense of the data in ways that would move beyond descriptive story telling. One structure emerging from the data findings was the differentiation of 'struggle' and 'fight', as I recognised that 'struggle' was found more in the area of 'personal troubles', whereas fight tended to be associated more with interactions around public provision.

Immediately following each interview, I wrote a short reflective account of the interview, identifying key ideas and themes that I had been aware of during the interview. I read these notes again before transcribing each interview to remind myself of my initial responses. Transcribing the interviews provided a first opportunity to listen to the interviews again in detail. Following transcription, I immersed myself in the transcripts in order to become thoroughly aware of their content, re-reading the transcripts and listening to the recordings. Later I listened to the recordings with the transcripts in front of me, stopping the recording to add marginal comments. These comments, together with my initial notes, were used as the basis for writing a summary of the interview (Savin-Baden, 2004). The summaries acted as an aide memoire and ensured I retained a sense of the person behind the text. A copy of the summary, together with the interview transcript, was sent to each participant for checking, with an invitation to make any changes the participant desired, including adding, deleting or changing the content. An example of a summary document is included in Appendix G.

I considered using software in the next stage of analysis and attended workshops organised by my university on the use of Nvivo software. I was wary of using a computer aided system, being aware that it can:

> …overly objectify as well as simplify the analytic process and risks devaluing and dehumanising the subjects at the heart of the research, including the researcher (Merrill & West, 2009, p. 144).

However I recognised the need for a means of recording and retrieving my thinking about the content of the interviews and identifying common themes and threads and was prepared to try the software, rather than simply dismissing it. I hoped that if I remembered the software was only a tool, it would offer a solution that could be worked with, but in practice, I found coding rapidly became mechanistic, distancing me from both the person and the content of the interview. Although software has the advantage of enabling complex searches, decisions about categories, segmentation and coding remain the responsibility of the researcher (Basit, 2003). It can be argued that a manual approach permits the researcher to identify nuances that would be difficult, if not impossible with a computer. Although this is practical with a relatively small dataset, as in this study, I do not dismiss computer-based solutions in other situations.

Having decided not to use Nvivo, I returned to the transcripts and engaged in further listening, interacting with the transcript by highlighting phrases, sentences and words that stood out as relevant to my research question without attempting to label them. Next, I took the highlighted segments and grouped them thematically. The themes and grouping of the themes was an iterative process, with groupings and new themes emerging over time. Appendix H is a table showing links between themes emerging from literature, practitioner interviews and parent interviews. Although this approach is not dissimilar to the initial stages of a grounded theory analysis (Charmaz, 2006; Glaser & Strauss, 1967), my sense was that I was undertaking a "systematic study of personal experience and meaning" (Riessman, 2002, p. 263). As I progressed through the transcripts, I found similar themes and storylines were arising. This permitted a grouping of ideas from different participants and a comparison of the perspectives of participants from different professional and practice backgrounds. I do not consider I was using a grounded theory approach but there are similarities between what I was doing and the iteration involved in inductive analysis, constant comparisons and moving back and forth between theory and data.

It was only after proceeding with my attempt to maintain a sense of both the person and the emerging themes, that I became aware of framework matrices as an approach to thematic analysis (Ritchie & Lewis, 2003; Ritchie & Spencer, 1994). Framework analysis uses a grid that permits data to be viewed either thematically or on a case-by-case basis. Although I had not used a grid, I recognised that framework analysis offered what I had been seeking in

permitting the researcher to consider the data thematically and to relate it to individuals. I experimented a little with this approach in checking I had identified the data pertaining to each of the themes identified as relevant to the 'struggle/fight metaphor', incorporating the themes identified during the sensing and understanding phases of the investigation.

When using data derived from stories told by parents and practitioners, the question of validity has to be addressed in terms of whether and to what extent the data can be trusted as an accurate representation of the underlying reality. Are participants telling the truth, a version of the truth, or describing what they think the interviewer wants to hear? In exploring the 'struggle/fight metaphor', am I assuming a certain version of reality and then confirming it by perpetuating a myth that the system is adversarial? I do not believe this is the case. It is clear in both the literature and in the stories that parents and practitioners tell that parents believe that they and their children are stigmatised; parents believe they have to fight for their children to gain the support they require; practitioners complain that the more articulate parents who make the most noise get the most support. Whether or not these statements are true, they are believed. Sykes suggests:

> The actual truth or falsity of the story is irrelevant: what is important is that the story and the ideas it embodies are accepted and *believed* to be true (1965, p. 323, emphasis in original).

This contrasts with the situations described by Sikes (2000) where participants appeared to knowingly set out to create stories which were known to be untrue, and were later shown to be so. In reality, there is no test of the veracity of accounts as all stories are constructions. Even deliberate untruths may be a construction of a desired reality. However, I would argue that some stories appear to have more basis in reality than others, some incidents may be told differently by others present, and some stories, which may appear dubious, still have a basis in reality. In considering my data, there was an internal consistency in the stories told by different participants, and that was reflected in the findings of other studies in the special needs domain, leading me to believe that the stories I collected are more than a subjective, constructed reality, but form part of the objective experience of those who work with or parent children and young people with AS/HFA.

Concluding reflections

By adopting a *systems* approach to understanding the meanings of the 'struggle/fight metaphor' in the special needs domain, I was able to use diverse methods and perspectives both in data gathering and in considering how to understand and find meanings in the data. This proved challenging, but also rewarding, as a richer picture emerged than I believe would have been possible using only more traditional approaches. Ashall wrote: "Individuals are free to make their own choices, but not the circumstances of their choosing" (2004, p. 24).

Practitioners choose to work in the special needs domain. Parents do not choose to parent a child with AS/HFA, but once they discover their child is different, they make choices, some of which involve struggle and fight. As will become clear in the following chapters, both parents and practitioners struggle. Some of those struggles are highly personal, others emanate from the way the system is constructed, and others from processes and resources controlled by those less directly involved in addressing the needs of children and young people with AS/HFA. Many struggles remain personal and private, whereas others lead to fighting for appropriate public responses to children's needs. Different people respond to challenging circumstances in different ways, at least partially dependent on their capital resources and dispositions, or habitus.

By locating the empirical study within the context of the whole *system*, it was possible to identify themes relating to the shaping of the domain that also influenced participants' experiences of the domain. This presented an opportunity to draw connections between the 'big picture' and the individual experience of the 'struggle/fight metaphor'. This approach also created a basis for considering what aspects of 'struggle' and 'fight' were most likely to change as a result of the draft legislative changes, and which aspects were probably more resistant to change.

Preface to the Findings and Discussion Chapters

Mills differentiated 'personal troubles' and 'public issues', using unemployment, war and marriage as an examples to explicate his meaning. Thus, he suggests, "if in a city of 100,000 people only one man [sic] is unemployed" (1959, p. 8), that is a 'personal trouble', but if thirty per cent of the population are unemployed, it is a 'public issue'. The former can be addressed by looking at the aptitudes and opportunities available to the individual, but the latter requires exploration of the way society is organised and consideration of structural change. He goes on to suggest that society is organised in such a way that teasing out the separations between the personal and the structural is increasingly complex:

> To understand the changes of many personal milieux we are required to look beyond them. And the number and variety of such structural changes increase as the institutions within which we live become more embracing and more intricately connected with one another. To be aware of the idea of social structure and to use it with sensibility is to be capable of tracing such linkages among a great variety of milieux (Mills, 1959, p. 10).

In Chapter Three I considered the structure and functionality of the special needs domain, recognising it as both a complex interconnected *system* and a *field* of struggle containing subfields that are separated from each other in various ways. The domain has developed subject to external and internal influences that have affected its structure and interconnectivity. In the following chapters, I turn from the structures to personal experiences of the special needs domain, recognising that some experiences are related to public or structural aspects of the domain, whereas others lie beyond the formal structures in personal or public spaces and places.

Having a child with special needs can be considered both a 'personal trouble' and a 'public issue'. There have been times in history when the birth of a disabled child was considered a personal disaster, but was addressed by a public solution; some babies were 'allowed' to die, some children were categorised as ineducable and incarcerated in institutions, more disabled children were sent to specialist residential schools (Roulstone & Prideaux, 2012). The social model of disability (Oliver, 2009) has done much to alter perceptions of disability, shifting the focus from individual impairment to recognising ways in which society constructs disability through the creation or permitting of disabling structures. Instead of disability and special needs being a 'personal trouble', they have become 'public issues' requiring public responses. However, it remains the case that the presence of a child with special needs in a family has implications for other members of the family and for relationships beyond the family.

Throughout the following chapters, I suggest that viewing experiences of the special needs domain in terms of 'personal troubles' and 'public issues' provides a framework for

differentiating the types of struggle present in the domain. Some forms of struggle are identified as primarily 'personal troubles', whereas others, requiring a statutory response, are considered 'public issues'. This binary differentiation offers a useful starting point, but in presenting and discussing my research findings, I suggest a more nuanced perspective is necessary as the boundary between personal and public is blurred. Although some personal troubles may be confined to the home, family or other private space, many personal troubles are experienced in public spaces where they are subject to public surveillance and comment.

Similarly, although struggle may have a tendency to be located in the personal realm, it can be experienced in both private and public spaces, meaning it is not possible to draw a direct connection between struggle and personal problems. Fight tends to have its origins in the public sphere in disagreements or confrontations between parents and public servants, but again these encounters cannot be considered only as a public issues as the problem continues to be experienced as a personal dilemma even when there is a public policy response.

In Chapter Six, I focus on the 'everyday struggles' of parents and practitioners as experienced in the personal space of the home and family and in the public places occupied by people on a daily basis, such as schools and school playgrounds, shopping centres, public transport, and parks and playgrounds. These struggles are identified as 'personal troubles', but in public spaces they cease to be private. When children exhibit inappropriate behaviour in public places, parents, familiar with dealing with behaviours in private, become acutely aware of onlookers, embarrassed on both their own behalf and that of their child, and conscious of needing to maintain their identity as a good parent. This sense of the problem no longer being purely private and personal is exacerbated when a child's behaviour affects others. Similarly practitioners discuss the personal dilemmas they face in dealing with a child behaving inappropriately, especially in classroom situations where other children or adults may be endangered. While questioning how best to respond to the child, practitioners have to deal with the issue when it occurs and in the public arena of a classroom. Such problems are not simply personal troubles, but neither are they public issues requiring statutory intervention. At times, such confrontations or troubling situations result in a 'hysteresis effect' for the individuals involved (Bourdieu, 1977; Hardy, 2008) as they experience a disjunction between what their habitus has prepared them for and their present reality.

Further blurring of the boundary between personal and public is evident in Chapter Eight where I discuss a number of situations that fall clearly into the public domain where problems require statutory responses, but the boundaries are less clearly demarcated than might be supposed. School exclusion, child protection and mental health issues are experienced in the private spaces of the family home. Even though the public response may take the issue into the public arena, the structures designed to deliver a public solution to a 'public issue' may

work in ways that result in unintended consequences to the possible detriment of children or young people with special needs and their families. Such public issues continue to be experienced as personal troubles, even when recognised and responded to by statutory agencies.

Differentiating the public and personal aspects of struggle and fight is only part of the story. It says little about why struggle occurs, or the range of different types of struggle experienced by those who work with or parent children and young people with AS/HFA, or the choices people make. In Chapter Seven, I use Bronfenbrenner's ecological system model (1977, 1986) in considering the social and cultural capital different participants have at their disposal before examining the actions they take in using this capital and accumulating additional capital. A number of situations are explored in the boundary zone between 'personal troubles' and 'public issues'.

Chapter Six

Special Needs: 'Personal Troubles'

Parents and practitioners participating in this study discussed a wide range of different types of struggle that they had encountered in their everyday experience of parenting a child with AS/HFA or working with children and families. The primary purpose of this chapter is to provide an overview of these experiences, differentiating these from the struggles that have the potential to develop into fight described in the following chapters, which are not part of the everyday experience of parents or practitioners. In viewing struggle in the special needs domain from the perspective of individuals, it is evident that not all struggles are the same, either in nature or in intensity. There is a sense in which the everyday struggles of parents and practitioners are an extension of 'normal' parenting or practice. Smith argues that underpinning the social model of disability is a conception of normal living and it is this ideal that the social model is aiming to implement for people with disabilities (2009, pp. 19-22). Implicit in many of the struggles described in this chapter is the notion that children who look the same as other children should behave the same way as other children. When they are not, they and their parents or other carers become the subject of public surveillance (Ryan, 2010), and subject to marginalisation and stigmatisation, resulting in a spoiled identity (Goffman, 1963; Gray, 2002; Ryan, 2010), and attempts are made by parents to regain and retain their identity as 'good' parents. For practitioners, struggle challenges professional values and may result in changes in practice. The struggles discussed in this chapter are considered 'personal troubles' (Mills, 1959) that tend to be experienced personally, at least initially, and in private spaces, such as the home, but may later be experienced and enacted in public places, including school settings and other types of space frequented by the general public, where they may blur into being of public concern, while not necessarily becoming public issues. Figure 6 shows this visually, with 'personal troubles' located in personal or public spaces, and remaining a 'personal trouble' even when enacted publicly. This diagram emerged from the data analysis and can be used in understanding and interpreting the data in this chapter.

In Chapter One, I wrote: "the 'struggle/fight metaphor' is not a term found in the literature, but is used in this study as a generic descriptor to denote adversarial relationships with and within the formal SEN system and areas of tension and struggle as experienced by parents and practitioners in the special needs domain more generally." Whereas the word 'adversarial' is used in the SEN Green Paper (DfE, 2011) in relation to the SEN system, participants in this study discussed many experiences of struggle and tension that did not relate to the formal SEN system and that took place both at home and in public spaces. Struggle formed part of the discourse of all participants, but had different meanings for

different people, some positional, and some relating to the specific circumstances of individuals. In this chapter, I address the question of how those involved in the special needs domain experience the 'struggle/fight metaphor' by presenting an overview of the types of struggle experienced by study participants.

In exploring 'personal troubles', I start by exploring the parents' experiences of recognising that their child is developing differently from other children and contrast this with the practitioner experiences of recognising difference. I then consider the formal recognition of a child as different through diagnostic and assessment processes. Finally, I explore the implications of living with difference for parents and how practitioners respond to children who are different.

	Private Space	Public Space	Outcome
Personal Domain	**Personal Trouble** *not requiring public (governmental) intervention*		**Struggle**
	Problem is contained within space, and owned by individual or family	*Problem, through public surveillance, ceases to be purely private, while not yet becoming a public issue*	

Figure 6 Locating 'personal troubles'

Recognising difference – parents' experiences of their very young children

People with AS/HFA have been described as "people with a disability who must deal with the social world as if they were not disabled" (Gray, 2002, p. 735), echoing the title of Willey's (1999) autobiographical work, *Pretending to be Normal*. Children with AS/HFA do not appear outwardly different from 'typically developing' children, but exhibit problems with communication, social interaction and empathy. These may exhibit as special interests, leading sometimes to the appellation of 'freaks and geeks' (Jackson, 2002) being adopted by people with AS/HFA or used of them. Sally spoke of her son's extraordinary memory:

> He had a little encyclopaedia and at the back of it there were a few flags and he just looked at these flags and memorised them all. So I bought him a poster that had 200 flags on, and he just memorised them all...You could name any country in the world and he could draw the flag - and these little tiny countries that I'd never even heard of and he could draw the flag.

Other children are resistant to change, have sensory sensitivities that can lead to a very restricted diet or finding some clothing impossible to wear, and experience difficulties making friends or 'fitting in' socially. Not infrequently, children with AS/HFA have difficulty understanding metaphors or other figures of speech, so may take an expression such as 'in a minute' literally. Some of these behaviours have led to children with AS/HFA being referred to as 'Martians' (Muggleton, 2012; Sainsbury, 2009) by way of indicating their difference from other children, using metaphors of living on a different planet or in a parallel universe. Many of these differences become evident once a child is in situations where they are expected to engage with other children, but parents in this study recalled incidents that indicated they were aware of their child being different from other children they were familiar with from a very early age, often predating the child's entry to the education system through preschool or fulltime schooling. These early differences were accepted and sometimes celebrated. Susanne recalled her friends describing Megan as "the model baby, she just sits and sleeps and she's really happy". Angela, Sally and Lynn spoke with pride of their children's early achievements, referring to an ability to complete complex jigsaw puzzles, an encyclopaedic knowledge of dinosaurs, and learning to read before starting school. Where a child's behavioural differences were less acceptable, parents found explanations for why their child was different from their friends' children. Angela related George's challenging behaviour to his gender: "all my friends had girls, you know, he's a boy." Lynn suggested Sam's difficulties might be cultural, being part of a British family living in Germany, but also recalled her surprise at how independent Sam was as a toddler:

> One of my earliest memories is of Sam, just as he was beginning to walk. I had gone to a playground with friends and their children. It was in a woodland location and there was a large sandpit. Other small children stayed by their mothers, exploring the sand, but not Sam. He started walking off into the wood and kept on needing rescuing. Throughout those early years, I spent a lot of time chasing after him as he showed no sense of needing to return to me.

For some parents, becoming aware of ways in which their child was different from other children, was the first step to recognising that their child's differences might have greater significance than just the reality that all children are unique and therefore different from each other. Linda contrasted David's behaviour with that of his older siblings: "David did things from a tiny baby that were different. He never ever put anything in his mouth". Naomi was alerted to the possible significance of Paul's differences by family members:

> My mother-in-law and my mother…were both mothers of more than one child that they had successfully raised, so when they were saying this child has an unusual difficulty getting to sleep, I knew that there was something more to it.

Most of the parents in this study were not unduly concerned by the differences they observed in their very young children, unless the child was behaving in a way that affected others.

Three of the eleven parents sought medical or other expert advice before their child entered fulltime schooling. In two of these cases, the parent was following a cultural norm in consulting a paediatrician; Naomi consulting a specialist in her native South Africa and Lynn living in Germany, where it is normal for children to attend paediatric clinics. Susanne spoke to her family doctor following an incident when her daughter, Megan, acted in a way that might have caused injury to another child:

> [Megan] was four in the June and it was after her fourth birthday. She pushed a toddler off a slide…I was in floods of tears because I was horrified at what she'd done. The parent of the toddler was horrified. And I thought there's something wrong here…I remember ringing my husband and saying there's something wrong with her, we've got to do something.

Very occasionally, a practitioner drew a child's differences to a parent's attention, perhaps suggesting the child might benefit from a medical assessment. Parents reported such interventions as bewildering, or making them angry. Angela was very angry when her health visitor suggested her son should be referred to the Child Development Clinic (CDC) for an autism assessment, and made a formal complaint, as she did not view the health visitor as qualified to make this suggestion.

Even though parents observed differences in their children, unless they did something that was both dramatically different and unacceptable, they did not consider their children might be different in any significant way from other children. Even those parents who consulted health practitioners did not anticipate that they might learn that their child might have a pervasive developmental disability. The parents' habitus had prepared them to recognise and celebrate difference, but not to look for difference that might have potentially serious implications. Research findings show that children with AS/HFA are often diagnosed much later than other children with ASCs or other special needs (Howlin & Asgharian, 1999; Howlin & Moore, 1997) and it is unlikely a parent would seek a diagnosis for a child they did not consider to be atypical, but just different.

Practitioner experiences

Some of the practitioners in this study had worked in the special needs domain for many years and had worked in settings where they were familiar with difference, but not necessarily with AS/HFA. The children they were dealing with were older than those just discussed, and were generally in school settings, but practitioners spoke of their first encounters with children they recognised as different from others they had encountered, and who, in retrospect, they considered would now be diagnosed with AS/HFA.

Brenda, a speech and language therapist, was employed in a hospital for the 'severely mentally subnormal' at the time when responsibility for the education of all children, including those previously considered ineducable, was passed to local authorities under the 1970

Education (Handicapped Children Act) (HM Government, 1970b). She spoke of gathering together "a group of interesting, non-communicating children" who would now probably have been diagnosed as being on the autism spectrum. At the time she reported that the advice given by medical practitioners was: "there is nothing you can do with this child, put them away". Brenda worked with one child, who she was sure would today be diagnosed with AS/HFA, whose mother had agreed to his hospital admission but:

> [She] was fighting for the support to be able to keep him at home because she was confident with the right input and management he could be kept at home.

Such encounters led Brenda to reassess her own practice, especially with those children who did not quite fit.

Mary was employed as a teacher in a school that was then designated ESN(M) but would now be referred to as a special school, at the time the 1981 Education Act (HM Government, 1981) was enacted, implementing the recommendations contained in the Warnock Report (DES, 1978). She recalled a child, whom she was convinced was on the autism spectrum, but her headteacher, "…said don't be silly. He's got a statement he's got moderate learning difficulties." Mary remains convinced that the differences she observed in that child would today lead to a diagnosis of AS/HFA. As a result of that encounter, and a training course the school sent her on, she went on to develop a special interest in ASCs.

Another teacher, Kate, who taught in a mainstream infant school in the early 1990s, recalled a girl in her class:

> Who had been identified as being difficult…but it was by no means clear that she was on the autistic spectrum and that was something that I would say I knew very little about.

Kate began to identify other children who were different from their peers:

> Not being able to follow instructions clearly and presenting in a very disruptive way…The child wouldn't be interested in anything that was said, [had] very poor concentration and basically was not conforming to any of the rules within the classroom.

As some of these children received diagnoses of an ASC, Kate undertook additional training and found that through experience, she was recognising other children as probably having ASCs.

Unlike the parents, the practitioners were sensitised to difference by their habitus, formed in part by their training and experience. When they observed differences they were unfamiliar with, they explored possible reasons for them and sought out further information. This led them to become more aware of ASCs and to recognise that being on the autism spectrum

might be an explanation for some of the differences they were observing in the settings where they were employed.

Labelling difference – medical diagnosis and assessment of SEN

There are two separate systems for the labelling of difference, one of which is medical diagnosis, which takes place within the health field, and the other is assessment of SEN, which is located in education, initially within the school, with the possibility of a further statutory assessment of SEN if in-school support proves inadequate. Figure 7 is a *system* map of the assessment subsystem of the special needs domain, showing the processes informing each other, the diagnostic process seeking reports from the school and the assessment process referring to medical evidence.

Assessment sub-system

Medical assessment

Developmental reports (health visitor, early years setting, school, other carers, parents)

Psychological assessments (clinical psychologist and educational psychologist)

Speech and language assessment (speech and language therapist)

Physical development (occupational therapist)

Social development assessment (health visitor, play therapist)

Medical assessment (Paediatrician or child psychiatrist)

Team Discussion leading to diagnosis

In-school assessment

Observations by classroom teacher, learning support assistant, special needs co-ordinator (SENCo), specialist teacher, educational psychologist

Testing by SENCo and educational psychologist

Monitoring individual education plan targets (IEP) and SATs results

CAF and/or TAF meetings

Statutory Assessment of SEN

Inputs

Medical reports

In-school assessment records

Educational Psychologist report

Parental report and additional specialist reports

Reports of CAF and TAF meetings

Outputs

Panel discussion of reports

Decision to write a statement

Naming school

Figure 7 System Map of the assessment subsystem (medical and SEN)

One objective of the SEN draft legislation (Secretary of State for Education, 2012) is the simplification of the assessment process and avoidance of multiple assessments where parents have to repeat the same information to different practitioners in different settings, some of whom have very similar job titles (DfE, 2011, 2012b). Multidisciplinary approaches are endorsed in the new guidelines for the assessment of ASCs in children and young people in the United Kingdom (NICE, 2011), but obstacles remain to formalising closer working relationships as the health service is funded and managed separately from the education system for the historic reasons discussed in Chapter Three, and there no proposals at present

to change this arrangement. Such structural arrangements can be confusing for parents who may be unsure who is responsible for what, or may find they receive conflicting advice from practitioners in different settings. It can also result in parents spending considerable amounts of time attending clinics and other assessment appointments (Rogers, 2007).

For most parents in this study, the first suggestion that their children's differences might merit further investigation was following entry to full-time schooling. Parents were invited to discuss their child's progress, or perhaps a behaviour problem, with their child's class teacher or sometimes the school SENCo. Mary, an infant school SENCo, spoke at length about getting to know children and parents before broaching her concerns about a child with a parent. Angela, who was so angry when her health visitor suggested a referral to the Child Development Clinic, had a very different response to the SENCO:

> I remember being in Reception playground with George and [the SENCo] coming towards me, and she says: "Hello you're George's mum." She said, "Do you want to come in and have a chat?" I have to say, I put it down to [her] that I must have had an amazing turnaround because back then obviously I was so naïve.

For some parents, the initial suggestion that their child might be a cause for concern was less sensitively handled. Sally became aware of concerns about her son in the more formal context of a consultation evening during Dominic's first term at Infant School. She was surprised to be questioned about Dominic's behaviour:

> I thought, well he's not naughty and he's very bright. So I was really surprised and I said, "I don't know why he does it." I just didn't have a clue, you know, what to do next, and I thought they were going to kick him out of the school.

Sally was able later to raise her own concerns about Dominic with the teacher, who would appear not to have been familiar with special needs:

> "Ooh, I don't know I'll speak to the Head." And then I got a phone call from the Head, and she said would I like to come in and see the SENCo. So I went in and met [the SENCo]. She was really lovely and she said to me, "Have you heard of Asperger's Syndrome?" He was only four.

For both parents and children these conversations marked the entry point into the formal processes of health and education special needs assessment. It was also the point when parents ceased to view their children as just different, perhaps a little eccentric, but typical children who were doing unusual things and began to consider what it meant to have a child who was different, and who would always be different, from others in their peer group.

Parental responses to diagnosis

Receiving a medical diagnosis involves parents moving from a position where they recognise their child as different to a place where their child is different, as confirmed by a clinician

(Vehmas & Mäkelä, 2009). Some parents want a medical explanation for their child's differences while others want to know why their child is different, sometimes blaming themselves (Gray, 1993a; Silverman, 2012). Parents in this study responded differently to both the initial suggestion their child should be referred to a paediatrician and to receiving a diagnosis. Angela was angry when it was suggested George be referred to the CDC:

> I was just, I was just mortified...I was like how dare you.

Linda was relieved to have an explanation for David's differences:

> It was like Alleluia! I didn't know anything about autism…but it was just a relief to know there was a name for whatever it was.

Sally was confused when Dominic was diagnosed with Asperger's Syndrome:

> You don't think of bright and autistic together.

Following Nathan's diagnosis, Carol:

> Just thought, yea it's as hard as you're going to make it. Look at him. He's not bothered.

Penny chose not to pursue a diagnosis for her son, taking the view Harry is:

> Further along the autistic spectrum than most people.

While unsure whether Harry met the diagnostic criteria, Penny preferred to avoid labelling him.

Some parents actively sought an explanation for their child's difference but experienced difficulty navigating the diagnostic and assessment systems, some of these difficulties moving beyond everyday struggles. Jenny was made aware of concerns about her son when he started school, but no further action was suggested. Jenny was able to use her social network and learned about SENCos, educational psychologists and child and adolescent mental health services (CAMHS) from a friend who was a teacher in another school. She met with the school SENCo, who agreed to refer James to the local authority educational psychologist for advice. The following months were frustrating for Jenny as she was not told when James was observed in school by the educational psychologist and was not made aware of the recommended strategies, despite Jenny's request to be kept informed. In addition, although James was also referred to CAMHS, there were delays in receiving an appointment due to lost paperwork. When an appointment was finally arranged, it was with Jenny and her ex-husband rather than with James:

> We sat with this man for two hours and he got us to fill out the Conners' questionnaire. I'd filled one out. [My ex-husband] had filled one out and the school had filled one out. And the consultant, I remember him putting these three completed questionnaires on the table in front of me and

> saying, pointing at it and saying, "Yours is the only one which shows he
> has ADHD. The other two from your ex-husband and the school don't
> suggest…" If I'm honest it's, it was very painful, very difficult…and after 2
> hours of talking to this doctor…he said "My conclusion is that there's
> nothing really wrong with James, but you're divorced…This must be some
> issues around your parenting technique." I remember walking out of
> there, and I turned to [my ex-husband] and I said, "There is no point. I
> do not want to take James to see this man. I don't care if he's consultant
> for the whole area for CAMHS. He is not going to give us a fair hearing."

Jenny was the only parent participating in this study who spoke of it being suggested that she was responsible in some way for her son's condition, a suggestion carrying echoes of Bettelheim's description of the mothers of autistic children as refrigerator mothers (as cited in Feinstein, 2010). Jenny went on to consult a paediatrician in private practice, who diagnosed James with ADHD and ODD (Oppositional Defiant Disorder) and later another private practitioner diagnosed Asperger's Syndrome. At the time of the initial diagnosis, Jenny said that the paediatrician told her that James was "one of the most complex children he's ever come across." Despite their early concerns, Naomi and Lynn also had difficult pathways to diagnosis for their sons, both turning to the private sector following problematic experiences with NHS services. Jenny, Naomi and Lynn were amongst the most high status parents in the sample, in terms of their occupations and level of education, yet they were amongst the parents who experienced most difficulty engaging with practitioners in ensuring their sons' needs were addressed. I return to this in Chapter Seven where I discuss the of the acquisition and use of cultural and social capital by parents.

Jane also turned to the private sector, not because of a problem with statutory providers, but because the suggestion that an assessment might be appropriate was made when John was in the final year of primary school, having transferred to a new school following bullying in his previous school. The school was unwilling to meet the cost of an assessment out of the school budget as John would shortly transfer to secondary school and paying for an assessment was considered inefficient use of the school special needs budget. As John's father had private medical insurance through his employment, this was used to obtain an assessment. Jane did not expect a diagnosis, anticipating the explanation for John's difficulties was the bullying John was subjected to previously. However, when the consultant made his diagnosis and explained what it meant, Jane had:

> No doubt in my mind that that was the diagnosis that fitted him. That
> explained this lovely little boy we'd got with all these sort of slightly odd
> characteristics. He didn't quite fit into the world.

Those families making use of private medical services were conscious that this was a choice that was not open to all parents. For some, like Jenny, there was a sense that it was wrong that they could get help because they had the means to do so:

> What do you do if you haven't got the money to go privately?

And being subjected to accusations that:

> It just shows what you can get if you pay for it.

These parents were also more aware than others of the contested nature of the diagnosis, as discussed in Chapter One.

Parents' early experiences of the SEN system

Most parents in this study learned about the SEN system and the support available in school through the SENCo, but there were some surprising variations in how much different parents knew about the SEN system. Parents with children whose SEN had been statutorily assessed and had a statement of SEN were generally more knowledgeable, especially those who had 'fought' the local authority in order to obtain the support they believed their child was entitled to. Amongst the parents whose children were not statemented, there was a general sense that the support being provided by the school was satisfactory. They were aware of statements and understood their children would not be eligible for one unless their needs changed, or were less adequately addressed when they transitioned to the next stage of schooling. Among these parents some confusion was evident as to what was involved in obtaining a statement, suggesting a lack of awareness of the statutory process for assessing SEN. Angela, a parent who facilitates a parent support group and considers herself knowledgeable about SEN provision, knew that her son had an Individual Education Plan (IEP) that was regularly reviewed. She had recently discussed statementing with her mother:

> I said Mum, "If I have to get him statemented, I will go down that route regardless." It's a bit like – I guess it would be like writing a Disability Living Allowance form. You've got to think of your worst, worst kind of day or whatever.

Further discussion revealed that Angela was not as well informed as she believed she should be about the SEN system, not knowing whether her son was on School Action or School Action Plus. I provided a brief explanation, as Angela was clearly frustrated and annoyed that the SENCo had not explained the formal SEN support structure to her. This is one small example of the struggle parents can experience, not only in accessing information, but in knowing what they need to know in order to support their children.

Although many children's needs are satisfactorily addressed without a statement of SEN, parents tend to view a statement as a way of ensuring the provision of services and support their children need. Those with statemented children know the statement is a legal document, and its provisions are enforceable in law. Parents were not always aware of their role in agreeing their children's IEPs. There was also uncertainty about reviews. Lynn commented that when Sam moved from infant to junior school, she asked the SENCo when

Sam's IEP would be reviewed and the SENCo expressed surprise that Lynn would want to be involved, as "most parents left it to the school". This may reflect pragmatism on the part of the school. The SEN Code of Practice (DFES, 2001) recommends IEPs should be reviewed at least twice a year. If this always involves meeting with parents, it could be very time-consuming for the SENCo and other members of school staff.

Linda, whose son was statemented, expressed concerns about how the formal review process was managed:

> The day of the meeting would come. We'd go up into [the SENCo's] little office and there'd be just me and her. We'd go through the items on the statement…I just wish I'd known more about it. She would say, "Oh right, this speech and language therapy. Well he's been doing very well with this. We don't feel that he needs this any more."…And I, not knowing enough, would go, "Oh OK right, fine."…A few things kind of disappeared off the statement.

Four of the parents in this study had children with statements of SEN at the time of the interview. A further two parents had children who had completed their secondary education and their statements were no longer extant. Another parent was awaiting the outcome of an application for statutory assessment and her son has since received a statement of SEN. Four of the parents had initiated the request for statutory assessment, and the school took the lead for the other three. Parents are not always aware that they can request a statutory assessment of SEN, or may feel it is better to wait for the school to act. In this study, three of the parents requested an assessment following advice from specialist advice agencies or having taken independent legal advice. A further parent requested an assessment with the support of her daughter's school, but the school itself refused to make the assessment request, but it is unclear why this was:

> Susanne: I approached the SENCo and said, "I'd like to apply for a statement" because nobody had bothered applying for one for me. I felt [Megan] needed one, and I felt we weren't going to get the secondary school we wanted if we didn't apply for one…I applied for one in January, and by June we had it, with the backing of the school, even though the school didn't want to apply for it themselves…
>
> Liz: You actually initiated it yourself?
>
> Susanne: I initiated myself – and I find I speak to many parents who say the same thing. Schools don't seem very willing and eager to apply for these statements, when children actually do need them. They're quite happy to sit back and relax and watch a parent have to go through all the stress of that as well as holding their family together and everything else.

Susanne felt that because she requested the statutory assessment of SEN, she had to do more work during the assessment process than if the school had made the request. However, once the local authority has agreed to carry out a statutory assessment, the process is the same whoever requested the assessment, in that the local authority requests reports from

the parents, school, educational psychologist, health authority and children's services and makes a decision whether or not to write a statement on the basis of this information. Parents may find themselves involved in further negotiations with local authority officers once they receive the proposed statement, particularly if they do not feel it adequately reflects their child's needs, or are unhappy with the description of the provision that will be made to meet the child's needs. If there are disagreements between parents and the local authority the parents can choose to appeal and/or enter into mediation as discussed by Runswick-Cole (2007a, 2007b).

Practitioner perspectives on diagnosis and assessment

Diagnosis is the responsibility of medical practitioners, usually consultant paediatricians or child psychiatrists, supported by other health practitioners, including psychologists and speech and language therapists (NICE, 2011).

Autism, a contested diagnosis – practitioner perspectives

Sarah, a clinical psychologist working in both health and education settings, observed that she had seen many children, in both school settings and the CAMHS clinic, where she had:

> …sat with them for about 10 minutes, thinking what they need is a social communication assessment. How has anybody missed this?

The children had been referred for help with obsessions, depression, or anxiety. Sarah recognised they needed support with these issues and that an autism spectrum diagnosis would not solve their other difficulties:

> Giving them a label doesn't make that go away. But I just struggle with why it's been missed, when to me it's really obvious that the underlying thing is that they just cannot work out other people…It seems to be so easy to miss in higher functioning children.

Sarah's observation raises the question of just how necessary a diagnosis is.

Autism is a contested diagnosis. It is not uncommon for children with AS/HFA to be diagnosed later than children with other forms of autism (Glazzard & Overall, 2012; Howlin & Asgharian, 1999), or to receive a different diagnosis initially (Gray, 1993b; Howlin & Asgharian, 1999). Some practitioners challenge whether autism actually exists other than as a social and cultural construction (Timimi et al., 2011). There are national guidelines for the diagnosis of ASCs (NICE, 2011), but these have to be interpreted by clinicians. The diagnosis given, or whether a diagnosis is made at all, depends on the diagnostician. John, a community paediatrician, was candid:

> There will be those who will only really diagnose very obvious and more profound end of autism and others who will diagnose children who actually don't warrant a diagnosis.

Differential diagnosis presents a challenge for practitioners, a particular difficulty arising when a child has been diagnosed with ADHD prior to assessment for an ASC. John explained there was a technical problem diagnosing autism and ADHD in the same child, as the diagnostic criteria "says you can't have the two diagnoses together." At the same time, in John's opinion there was an overlap between the two conditions and he had diagnosed children with both autism and ADHD.

Differential diagnosis involves not only deciding the appropriate diagnosis, but also identifying whether problematic behaviours result from an ASC or if there are other factors to consider. Sonia is now a senior manager of a specialist residential school, but earlier in her career worked with adults with mental health problems. She recalled working with a man, whom she believed to be on the autism spectrum. He had no formal diagnosis and some of Sonia's colleagues actively rejected the possibility of a diagnostic assessment:

> Everything was put down to his race…I found that incredibly frustrating…Nobody bothered to peel back the layers…There was a black social worker involved who was adamant that we shouldn't question anything that related to colour…For me it was nothing to do with colour…This happened to be a black man, but he had needs and he had issues.

In practice, the diagnosis of AS/HFA is often little more than a formal recognition and label for difficulties and differences that are familiar to those close to the child. As Joan, an educational psychologist, pointed out, having a diagnosis does not guarantee a child will receive any additional support in school. She suggested that if parents were aware that a diagnosis would not make a difference:

> Some people will choose to leave it then and say well, why label a child if it's not going to get them anywhere.

Additionally, a medical diagnosis of autism does not necessarily result in any further therapeutic involvement.

"In denial" – power and partnership

Some parents are resistant to diagnosis and practitioners are cognisant that parents have to cope with their personal feelings and attitudes when their child receives a diagnosis of a pervasive and lifelong developmental disorder. They may avoid making a diagnosis if it is considered the child's behaviour and condition can be managed without a diagnostic label. However there can be other reasons for not diagnosing, or not diagnosing initially, as when health and education practitioners describe parents as 'in denial' about their child's autism, or speak of them as unready to accept a diagnosis. Parents use the same language, Angela describing herself as having been in denial, when it was first suggested her son should be assessed. John, a community paediatrician, spoke of a family the CDT was working with:

> Where we feel quite strongly the child has a diagnosis and school do too and the parents are almost looking for any other diagnosis except autism.

Joan, an educational psychologist, spoke of parents who had accepted their child's differences and adapted their lifestyle to meet the needs of the child in the home and family, but did not:

> …really accept the sorts of issues that maybe they're presenting with when they're in a school setting or another situation, and they're not very keen for a diagnostic label.

It is relevant to consider what lies behind the use of such expressions as 'in denial' or 'not ready' by practitioners in relation to parents. In an exchange of emails, Sara Ryan suggested the phrases stemmed from paternalistic attitudes and represented the desire of some practitioners to 'protect' parents:

> I think paeds [paediatricians] who report that 'parents not ready' line is an example of paternalism really. I've had conversations with a paed about a study I was tangentially related in involving parents of children with CP [cerebral palsy]. One of the key findings was the anger parents felt when their children's records revealed that the diagnosis was discussed in medical circles a good six months before it was raised with them. The paed said this was to a) to protect parents and b) not to overly alarm the 25% of parents whose children would go on to not have CP after all. I always felt that this indicated a less-value status accorded to the 75% of parents with CP kids (Ryan, 2011, quotation marks not in original).

This thinking is reflective of the power relationship present in the diagnostic interview and can obstruct meaningful partnership between practitioners and parents. Medical practitioners and parents focus on the needs of the child and, in particular, on ascertaining the nature of those needs so they can be appropriately addressed. Both have expert knowledge, the parent in relation to their own child, and the medical practitioner based on knowledge of other children and on the knowledge of other practitioners shared in training or written materials, and, in addition, the medical practitioner has expert power. Classically power resides in the doctor: "Trust in the superior medical knowledge of doctors is likely to lead their patients to accept diagnosis and advice" (Scott, 2001, p. 15), the patient being a 'passive agent', reliant on the doctor's expertise and capacity. In the case of a child with special needs, a parent may not be passive as they bring knowledge and evidence to the diagnostic process. The parent, as the expert on their child, may choose to disregard the medical perspective, or seek a second opinion, or use treatment strategies not formally supported by medical practitioners (Silverman, 2012).

Although practitioners acknowledge parents' expertise, in terms of status, position and cultural capital in the health field, medical consultants have the highest status with the most cultural capital. Other practitioners occupy different positions in the health hierarchy, with parents having little status or capital, despite guidelines and codes of practice emphasising

partnership and consultation. Regarding parents as being in denial, or discussing children in private conferences, or withholding information, reinforces the power differential and hierarchy within the *field*. Although there is evidence, as discussed in Chapter Eight, of parents engaging in open conflict with education practitioners, there was no evidence in this study of open conflict with health practitioners apart from Angela's formal complaint about her health visitor when it was suggested her son should be referred to the CDC for assessment. This may be suggestive that the power, position and status of health practitioners is viewed as legitimate in ways not attributed to education practitioners.

Education practitioners also refer to parents as being 'in denial'. Kerry, a teacher in the reception class of a local authority special school for children with autism, used the phrase in relation to a parent whose expectations of her child were different from hers. The parent had asked about her son's potential, in terms of what he might achieve in future, asking if he had the ability to become an accountant. Kerry identified a disjunction between her expectations of the child and his parent's aspirations, as she considered the child's potential in the context of the achievements of young people in the further education section of the school, some of whom had trained to work on tills and found employment in supermarkets:

> So there's me sitting there thinking, "Iffy about supermarket," and she's asking me if he's going to be an accountant. And because she said: "Oh I don't want him working in a shop…that's below him." So she was in complete denial.

In further meetings, the parent continued to focus on scholastic achievement in discussions with teaching staff, while their focus was on behaviour and focusing in class. There was a clear discrepancy between the school targets for the child and his mother's aspirations. The question is raised in the SEN Green Paper (DfE, 2011) of whether too little is expected of children with special needs. This child was at the beginning of his school career. The account raises the additional questions of when it is realistic to assess a child's potential and when, if ever, to hypothesise about a very young child's future. Kerry made a realistic and objective assessment based on what she knew of the child and the life-course trajectories of past and present pupils. An alternative interpretation of the parent's perspective is not that she is 'in denial' but is embracing the paradox of recognising and accepting her son's disability while having high aspirations in order that he might attain his full potential (Larson, 1998).

SEN assessment - support and resource provision following diagnosis

Once a child has received a diagnosis of AS/HFA, they may continue to attend review appointments at the CDC or CAMHS, but are unlikely to be offered any ongoing therapeutic intervention as ongoing support tends to be focused on provision in school. This may include, for example, speech and language support, provided by classroom-based practitioners following programmes devised by health service SLTs. Decisions about the support children

with AS/HFA receive in school are made in school, sometimes in consultation with specialist staff employed by the local authority, or by the local authority in consultation with the school and specialists from within the local authority, or elsewhere including health service practitioners. As school-based practitioners are part of the education system, it might be anticipated that they would have little difficulty traversing the SEN system, but this is not always so in practice. Mary, an experienced SENCo working in a mainstream school with previous experience in special schools, spoke of the difficulties she encountered working with the local authority officers and specialist staff and keeping up to date with policy changes:

> I think the most difficult thing for us in schools is that people's job titles change constantly and the people in those posts change…They can change overnight and you think, "I don't even know who this person is." Or that post can disappear. And that's the most difficult thing…getting through that minefield of people to get to the right person.

Mary also drew attention to tension between education officers, responsible for deciding what services and resources were necessary to support a child, and health service personnel, who may have strong views on the needs of a particular child and how they should be met:

> They don't like it if the paediatricians make a recommendation. I've heard them saying, "Well, they're not education. How dare they make these comments about this child?"

As a school-based practitioner, Mary sometimes found she was working more closely with members of the CDT, than with her local authority colleagues in the education service, and her sense of separation from the local authority is evident in her use of "they" and "them" when referring to local authority officers. Mary's comments also suggest that whereas collaboration may be effective at a practice level, it may be less so when non-practitioners are involved, such as local authority administrative staff.

Those practitioners based in school settings, but not immediately involved in the formal SEN processes were vague about how they functioned in practice. Kate, an experienced infant school teacher, acknowledged her limited understanding of the SEN assessment system:

> I read reports from the specialists, so I might have an ed. pysch. [educational psychology] report or a speech and language support or paediatric doctor's and so on. So those are the reports that I would read…I don't have a great awareness in all honesty. What I am aware of is through our SENCo having conversations with me.

In a situation where practitioners are unsure who is responsible for making what decisions, who to speak to within the local authority, and what the precise role is of other practitioners in their own and other organisations, it is perhaps unsurprising that the SEN domain can feel complex and confusing to parents who are far less familiar with education and local authority structures.

In summary, there is evidence of both parents and practitioners finding engagement with the formal SEN processes challenging, but the experience of medical diagnosis presents fewer difficulties for parents, while presenting challenges to practitioners. It may be that the health service is more familiar territory to both parents and practitioners than the education systems. Whereas adults tend to have some awareness of visiting their GP and being referred for a specialist assessment, knowledge of the education system may be limited to their own schooldays. It would appear that both parents and practitioners have to learn a different language and set of rules when they engage with the assessment process. In Bourdieusian terms, both school-based practitioners and parents were entering a new *field*, and one where they need additional cultural capital, in the form of knowledge and understanding of the decision making structures, and where they experience disjunction, which could lead to hysteresis, where their dispositions, or habitus, are reshaped by the new circumstances and encounters. This is explored further in Chapters Seven and Eight where more complex struggles are discussed.

Living with difference – marginalisation, stigma and secrets

Although parents accepted and sometimes celebrated the differences they observed in their very young children, they began to view their child's differences as a cause for concern if they affected other family members adversely or if their behaviour proved problematic outside the home. Such incidents tended to occur as the children grew older and behaved differently from 'typically developing' children in ways which affected siblings, led to public approbation and created difficulties adjusting to the requirements of the school and community. Parents had to adjust their expectations of social life for themselves and their children. The habitus of parents did not equip them for the possibility of a child who might look the same as other children, yet have a hidden disability. This section explores the life experiences that shape the habitus of parents of children with AS/HFA, leading them to identify themselves not just as parents, but also as parents of disabled children. I focus on family life, social relationships and friendships, and public surveillance.

Family life – siblings and secrets

Jenny and Susanne both talked of how their other children had been affected by being involved in the care and support of a sibling with AS/HFA. Jenny recalled an incident when she had been alone at home with her three children during a holiday period and was unable to summon other adult help when James had a 'meltdown'[11]:

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[11] 'Meltdown' denotes a situation where a child loses control in ways similar to a toddler tantrum, but at an age when such behaviour is regarded as inappropriate. It may be caused by sensory overload, stress, anxiety, or the cause may not be readily identifiable (Ryan, 2010).

> I had to restrain [James] for something like two and a half hours…The other two children were helping me to restrain him. I can remember saying, "You shouldn't be restraining your little brother. You shouldn't be here."

The older children both experienced difficulties in school. As James's behavioural difficulties became known within the school community, his siblings were associated with his difficulties, resulting in them becoming socially isolated. Such marginalisation by association is referred to as courtesy stigma (Goffman, 1963). Not only children are marginalised in this way. Parents may find they are excluded from the friendship circles that develop amongst adults in the school playground. Both James's siblings went on to self-harm and require counselling and Jenny related their difficulties directly to their experiences with James.

Susanne's younger child was affected by her sister's condition. Susanne's older daughter, Megan, was diagnosed with an ASC shortly after starting school and, as is not unusual in children with ASCs, later developed a comorbid condition (Blacher et al., 2003) when she began to have epileptic seizures. Megan and her parents had to attend many medical appointments and three-year-old, Poppy:

> …got palmed off left right and centre to grandparents, neighbours, every time we had to go to hospital.

In addition, Poppy was asked to "keep an eye" on Megan, and alert her parents if her sister showed signs of having a seizure or going into a 'meltdown'. During the interview, Susanne said Poppy was now showing signs of stress and required mentoring support in school, but also expressed her own ambivalence about what it was appropriate to expect of Poppy, acknowledging that "at seven years old, she's carrying an absolute weight of worries on her shoulder," but believing "siblings look out for their sisters and brothers." Susanne had an expectation of normal family life, based on her habitus, which had been formed by her own experiences, but this expectation was challenged by her experience of the effect on Poppy of being involved in looking after her sister.

Having a child with an ASC does not only affect siblings but can affect other family relationships, including relationships with partners. Though none of the participants in this study suggested that their struggles with their child was a cause of relationship breakdown, Susanne commented that Megan's condition was a source of tension in her marriage:

> How the heck my marriage is still together is beyond me to be honest because I've got him moaning about marital responsibilities and I'm like, you got to be kidding.

Again, none of the parents in this study spoke of grandparents being other than supportive, but John, a community paediatrician, said problems could occur when grandparents do not acknowledge a grandchild's difficulties:

> The number of times you'll hear parents saying they know they've got a problem but the grandparents won't believe it and just see them as not doing their parenting job properly.

Situations may arise where a child's disability is kept secret within the immediate family. Penny, a professional carer with a son who is probably on the spectrum, now knows her adult cousin has a diagnosis of Asperger's Syndrome, but this was kept secret within his immediate family during his childhood, despite regular contact between the two families. Penny only became aware of her cousin's diagnosis when she was asked, because of her professional knowledge, to support him in accessing services. Penny's aunt has accepted Penny's support and acknowledges similarities between Penny's son and her son when he was younger, but she still does not speak openly of her son's diagnosis. She also refuses to accept that he may require any form of psychological support, as this would imply he was mentally ill, though she is happy to accept interventions that relate to his physical wellbeing. It appears Penny's aunt continues to view mental health as stigmatising, and does not want to be marginalised by association. It can be hypothesised that some of Penny's reluctance to seek a diagnosis for her son is influenced by her family background and the family attitude to her cousin's diagnosis, but this would be speculative rather than evidence based.

Social relationships and friendships

Parents spoke of ways in which their child's AS/HFA had restricted their child's capacity to form friendships and to engage in the social activities their peers engaged in. For some parents, their own opportunities to make new friends and engage fully in the social life of the school and community was limited also. Some difficulties stem from children with AS/HFA not understanding social relationships and social behaviour and others relate to the negative labelling of some children on the autism spectrum as 'naughty' by their peers. Although schools teach children about disability and adopt an ethos of affirming difference, this does not remove the problem, as Kate, an infant school teacher, explained:

> We've had to do a lot of work…with the rest of the class to try and explain that particular child has got his own problems…They're described as naughty children by the children themselves. Probably when they go home, they say to their parents, "So-and-so has been naughty today."

For parents of children with AS/HFA, this can mean they receive reports of their child's misdemeanours from other children at the school gate. As a child gains a reputation for poor behaviour, or being naughty, they receive fewer invitations to play and become marginalised and increasingly socially isolated, which can lead to further behavioural problems as children with AS/HFA tend to want friends, even though they may not understand the conventions of friendship. In addition, parents may also be stigmatised through exclusion from parental friendship circles. As children with AS/HFA may not be diagnosed until some time after commencing school, this marginalisation cannot be construed as disability discrimination, but

can be associated with the development stage of children starting school, when they are learning to differentiate good and bad behaviour, and with parental aspirations for their children. Parents accumulate social capital when their children succeed. Parents of 'typically developing' children may not want their children subjected to the negative influence of less well-behaved children as that may lessen their children's chances of being socially successful in the school environment, reducing their capacity to accumulate social capital, and also reducing parental social capital (McKeever & Miller, 2004; O'Donoghue, 2012).

Jenny described the isolation she experiences as the parent of a child with special needs:

> The other thing I think often gets forgotten is that schools are often part of small communities...We're a sort of urban village where I live. Everybody knows everybody else. I had three children going through that school. Everybody knew who we were and the gossip that was going round about us because of James and the way he was behaving...It was very, very adversarial and antagonistic and unpleasant...I live 2 minutes walk from the school. I have to pass it every single day and it's very, very, very difficult. Very difficult. It's affected all sorts of relationships I have with people in the community there...You end up being kind of isolated in a way because you have this problem and this difficult child. But then there's another layer of isolation that happens because you get cut off from the community.

Some parents were struggling to maintain the friendships they had developed with other parents. Sally, the mother of Dominic, a ten year old diagnosed with Asperger's Syndrome, had a number of friends with children of a similar age to her son. When Dominic was younger, she was able to combine meeting her friends with the children playing together, but as Dominic has grown older, he has chosen to withdraw from this contact, saying:

> Just because you've got your friends, why do you think I want to play with their children? I don't want to play with their children. I want to stay at home on the computer. You're ruining my life if you go and make me play with their children.

Currently, Sally has resolved this problem by arranging for friends to visit her in an evening when the children are asleep, but she recognises finding solutions that enable her to maintain her friendships may be more difficult as Dominic gets older. She expressed concern that Dominic's unwillingness to socialise diminished not only her opportunities to meet socially with other adults, but his potential friendship circle, this reduction in the size of their social network also reducing their social capital.

Linda had benefited from a supportive friendship circle. When David started school Linda was concerned that she would be isolated, as she did not have an existing circle of friends as David did not attend preschool. A neighbour, with a child starting school at the same time, invited Linda into her friendship circle, and that group has continued to support Linda as it became clear that David was developing differently from his peer group. She related an

incident when David had a 'meltdown' in the playground before school and had been screaming, shouting and hitting and kicking Linda:

> Oh absolutely dreadful you know. Everybody looks at you, and you just think, "Wish the ground would open up and swallow me."

When she collected David from school, one of her friends told her she had had to go into the school office that morning, where another parent was talking very critically about David 'kicking off':

> My friend turned round to her and said, "You really should find out the facts before you start running people down. He's autistic and it's not her fault." You know, really stood up for me.

Although Linda struggled with David's behaviour, she had a strong network of friends, enabling her to accumulate social capital. In a difficult situation, her friends supported her, not only enabling her to retain her identity as a 'good' parent, but also shifting attention to the other parent, similar to situations described by Ryan (2010), when parents 'out' their children as autistic, when subjected to negativity in public spaces.

Public surveillance

Parents who know their child can behave in ways others find socially unacceptable may avoid the risk of coping with difficult situations in public by limiting the extent to which they participate in social activities (Gray, 2002) or may protect themselves and their child from adverse reactions by 'outing' the child and their condition (Ryan, 2010). Ryan observed that strangers use "stares, glares or comments to inform children and their caretakers that their behaviour is not acceptable" (2010, p. 868), describing this as the enactment of a shared communal responsibility for ensuring children comply with communal norms.

During the period before Dominic was diagnosed, Sally found it increasingly difficult to engage in social activities with him. Although she accepted his difficult behaviour, and had developed coping strategies, she found it problematic that she could not give a satisfactory explanation for that behaviour. She described a train journey where she felt accountable to strangers for Dominic's behaviour:

> We went up to London on the train...It didn't occur to me that this train would be really busy...There weren't seats together. I don't know if it's just that [Dominic] couldn't cope with the fact that it wasn't as he expected, that he thought all four of us should sit together, that he just started lashing out big time…He was kicking me in the back. I tried to ignore it because I knew from experience that that was the best way to deal with it, but all these people on the train were watching and they were tutting.

Although Sally found this attention uncomfortable and intrusive, she was able to ignore it:

> Then the woman over the other side, next to my sister, said, "Has he got a problem?" This was just before he was diagnosed, so we suspected, but we didn't know for certain.

It was more difficult when a stranger asked a direct question, and this difficulty was compounded by Sally's lack of a straightforward explanation, combined with not wanting to have to give account to a stranger, but feeling obliged to do so. For Sally, receiving a formal diagnosis provided a way of explaining Dominic's behaviour, but she has gone beyond this in obtaining cards from the National Autistic Society (NAS) that offer a brief description of Asperger's Syndrome. Sally gives these cards to people who respond negatively to Dominic in public spaces, viewing this as a way of increasing public awareness of autism, in contrast to the parents discussed by Ryan (2010) who 'outed' their children in order to redirect the public gaze from their child to the other.

Linda also experienced situations where strangers responded negatively to David's behaviour in public places. Like Sally, she felt such strangers were demanding an explanation for David's behaviour, whether or not this demand was articulated. On one visit to the local town centre:

> We walked past the bus queue and [David] was getting angry because I wouldn't buy him something, and he just stopped and looked at me and went, "I'm going to just stab you then. I'm going to get a knife and I'm going to stab you."…There was a whole queue at like two bus stops together…Everybody just looks at you and you think, "Well I shouldn't have to justify myself to all these people," but at the same time you think, "Well I just look so bad. I look like such a bad parent." And that's the thing isn't it, it's how it makes you feel.

Parents may be able to limit the exposure of themselves and their children in some contexts, but one public place it is difficult to avoid is school. A particularly difficult time for some children with AS/HFA can be school transitions. Sally spoke of Dominic's first day at junior school. Throughout the school holiday, she had tried to prepare him for the change, but Dominic had been insistent that he was not going to his new school:

> "It's a stupid school. oh I'm not going there."…[He was]…getting really angry about it.

On the first day of term, Sally had to "drag him into the hall" and Dominic sat under her chair:

> The Head said, "In a minute we're all going to wave goodbye to our mums [sic] and the mums will walk out of that door and we're all going out of this door."…All the children went and all the mums went and there was just me left in there with Dominic under my chair…Then I just had to go and leave him. I remember, I got in the car, burst into tears and cried all the way to work, thinking, "Why me? Of all those children."

In these incidents Linda and Sally both felt subjected to a negative public gaze that stigmatised them and their children. Even though neither mother had done anything wrong and both were well aware of their child's challenging behaviour, they were both conscious of how they would appear to others. Linda was aware of not having an adequate and easily communicable explanation for her son's behaviours, and simultaneously experiencing the tension between a requirement to explain her situation to strangers and resentment at being held to account by people who did not know her or her child. Sally knew she would have to continue to face the parents and staff at Dominic's new school. Both felt they were perceived as 'bad' parents as they could not manage their child's behaviour. Other parents in this study commented that life would be easier if their child's disability was visible. None went as far as some parents in Ryan's (2010) study who 'outed' their children by putting T-shirts on them with slogans such as "I'm not naughty, I'm autistic," but, like the parents described by Farrugia (2009) and Ryan (2010), the parents in this study expressed discomfort when their children behaved in publicly unacceptable ways in public spaces.

Responding to difference in public contexts - school

The practitioners who most often cope with children's differences in their everyday work in classroom situations are teachers and LSAs. They face the challenge of differentiating between a child being 'naughty' and a child behaving inappropriately due to factors such as special needs or disability. Apart from learning and teaching, schools, and in particular reception classes, have a major role in enculturating children into the school and education system. In discussing behaviour issues, education practitioners identified tensions between treating all children the same in applying sanctions, responding to the individual needs of different children and ensuring the health and safety of all the children in a classroom. Teachers, in particular, were aware of their responsibility for the whole class, and discussed the need to have sufficient adults present in a classroom to manage situations appropriately.

Various approaches were taken to avoiding or dealing with behaviour problems, dependent to some extent on the school setting. All the education practitioners referred to the use of sanctions, but some emphasised avoiding behavioural difficulties through classroom management and awareness of the responses of different pupils to each other, an approach which was arguably more achievable in specialist settings with smaller class sizes. John, an LSA in a specialist residential school, spoke of classroom dynamics, and controlling "where each boy sits, depending on their interactions with those around them" in order to defuse potential problems.

When behaviour difficulties could not be prevented, sanctions were imposed, but not all teachers were confident of the effectiveness of sanctions, especially with children and young

people with AS/HFA. Pam had worked for many years as a SENCo in a mainstream comprehensive school before moving into a specialist setting. Her comments reflect her uncertainty about the value of sanctions, with the implication that imposing a sanction did not enable a young person to understand, or change, their behaviour:

> I'm not sure the sanction works…Certainly I think debriefing is important…If you know why you're doing it, you stand more chance of stopping yourself.

Other teachers, like Kate, a mainstream Reception teacher, welcome the use of sanctions, viewing these as a way of making children aware of consequences:

> You can enforce consequence…Before, when there was no person there to enforce to that child that they must do what you've said, that child really is running on their own agenda. I think even a child with Asperger's Syndrome responds a lot better to having those parameters. It calms them.

Conversely, it could be argued that if the consequence of inappropriate behaviour is an externally imposed sanction, it is unclear whether this actually assists the child in understanding why the behaviour is not acceptable, especially if the reason for the required behaviour is not understood in the first place.

The ultimate sanction for managing behaviour difficulties in school is exclusion. Children with AS/HFA are subject to a higher number of fixed term and permanent exclusions than other children (Reid, 2011). Some children are not excluded from the school premises, but receive an in-school exclusion, or are otherwise excluded from engaging in school life (Webster & Blatchford, 2013). Practitioners spoke of children who were physically present in school, but did not participate in school life in any meaningful way because of significant aggressive and behavioural problems. This was accepted as a way of managing a problem, but practitioners were well aware that this approach did not address a child's needs. Such behavioural sanctions do not only affect the child, but, as discussed earlier in this chapter, may affect the social positioning of their siblings within the school, and the social positioning of the family within the community.

Mary, a SENCo in a mainstream infant school, spoke of a boy with an ASC, who was contained in school in order to avoid exclusion, but was effectively excluded from all school activities:

> …with the blessing of the educational psychologist and the speech and language therapy manager, [he] was not in the classroom at all the final term. We had battled with the LEA officer to get a placement for this child and couldn't. This boy had huge, huge problems. And then he was out of school at least 18 months and then went to two special schools that excluded him.

It is impossible to say whether this child could have been included in a mainstream classroom with appropriate support, but the story reflects the finding of other research in this area, that the integration of some children with special needs in mainstream schools may result in exclusion in practice (Ainscow, 1995; Moriña Díez, 2010; Shah, 2007). In this particular case, at least part of the reason for the child being in this situation was a shortage of appropriate resources and provision. School exclusion is returned to in Chapter Eight.

Practitioners and personal struggle

A surprising finding of this research was that it is not only parents who confront personal challenges with children with special needs, but practitioners also spoke of the personal struggles they experienced working with children with special needs. They spoke of guilt and regret when they reflected on how they had responded to children earlier in their careers, of adjusting their view of children with AS/HFA through working with them directly, and of ways in which they had adapted their working environment to ensure they gave additional attention to some children.

Pam, a teacher with many years experience as a SENCo now working in a specialist residential school, spoke in some detail about children she taught early in her career, before she was aware of autism, recognising these children would now probably be diagnosed with AS/HFA. She recalled a boy, referred to as 'Edward':

> I remember very clearly the first boy who I realised was – I mean, I didn't know there was an autistic spectrum then, I don't think. You know, it's dreadful to say but – and it's only 20 years – and we just thought he was slightly odd even then.

Edward spent a lot of time in Pam's room drawing detailed pictures of trains and railways. The pictures always took the same form and when complete:

> …he would dump it on my desk and say, "Right, now I'm going to go and lie under a lorry outside."

Pam expressed regret she had not been able to help Edward more effectively due to her lack of knowledge of autism, and also shame that she now knew she had responded inappropriately to him and other young people:

> It made me in some ways quite ashamed that perhaps the way I had been teaching and disciplining some boys was completely wrong…Had I been more aware earlier, I would have done lots of things differently.

Other practitioners gave equally detailed descriptions of children they had worked with early in their careers, whom they now identified as probably on the autism spectrum, but who at the time were either not diagnosed at all, or received a different diagnosis, but one that was viewed as appropriate at the time. Practitioners spoke of their lack of knowledge of ASCs at

the time they encountered these children and initiatives they had taken seeking additional training and information. As practitioners, they knew how to access training and were able to use their accumulated professional and cultural capital to acquire further knowledge. Although they recognised this had benefited children they had taught later in their teaching careers, they recognised continuing gaps in their knowledge and understanding of ASCs. Kate, an infant school teacher, spoke of finding it difficult to recognise girls in her classroom who might be on the spectrum. Pam found she made comparisons between the boys in her current school and 'Edward', sometimes wondering how life might have been different for him, if his autism had been recognised and he had been able to attend a specialist school.

Mike had recently become head of mathematics in a specialist school, previously having worked in comprehensive schools. He was very aware of the differences between the mainstream setting and the specialist school setting. In the mainstream school, teaching a mixed ability classes with large numbers of pupils, Mike found it "…very difficult to identify the learning targets, to do the necessary observations and to work out the necessary learning strategies."

By contrast, in the specialist setting, he was finding it was possible to "have the time to think, reflect, modify and improve on not only your own learning techniques but researching new ways of teaching."

He found his approach to teaching had been re-energised:

> I want to learn more and more about autism and the challenges of education with autism…I love teaching here. I find it extremely rewarding, mainly because it's not just the art of teaching, it's learning how to teach in a challenging and what I find a very rewarding area of education.

Sarah, a clinical psychologist, was frustrated by scarcity of resources and the need to ration the support given to children and their families. Some of this rationing was achieved by restricting the amount of information parents were given about support and resources, differentiating herself from her employing agency in describing the agency as rationing services and expressing her own discomfort at some of the methods employed in order to control expenditure:

> Money is tight and they like to ration it and sometimes it's rationed by actually not giving out very much information and by putting parents through a very extended process that perhaps is unnecessary.

Some of the challenges faced by practitioners were in connection with their relationships with other practitioners from other disciplines or working in other organisations. Mary, an infant school SENCo, and Kerry, a teacher in a special school, both expressed concerns over the power they felt some practitioners had in relation to decisions about children, even though

their involvement with those children might be limited. Kerry contrasted working with specialist practitioners employed within the school with those based elsewhere:

> We have in-house speech and OT [occupational therapy] and because they work with the children on a weekly basis they know the children quite well and therefore it's much easier to work collaboratively with them…In terms of other professionals, it's not so good – sort of social workers, ed. psychs. [educational psychologists]…They don't really know the children so they're making assumptions based on what they think they know or paperwork they've read…They literally come in and they might go and sit and watch the child for like ten minutes and they're supposed to sort of help make this decision that's going to change the child's life.

Practitioners also recognised their roles could be problematic. Joan, an educational psychologist, acknowledged practitioners in her role might be viewed as gatekeepers, but viewed her role as advice giving:

> …to schools on what the criteria is for statutory assessment in our county…[and psychological advice]. We're really one of the few professions that can really provide a view on somebody's cognitive ability.

The personal struggles and challenges encountered by practitioners differ from those faced by parents. Whereas the challenge of raising a child with AS/HFA impacts on all aspects of parents' lives, the challenges faced by practitioners are confined to their professional activities. Nevertheless, practitioners did respond personally to the children and situations they encountered during the working day and some carried a burden of guilt that they had failed children in the past, sometimes increasing their commitment to address the needs of children they worked with now as effectively as possible. Practitioners recognised gaps in their knowledge of AS/HFA and that they might provide a better service if they knew more, but they also recognised problem areas they had little influence over, such as equitable access to support resources. There was some evidence of some practitioners experiencing tension between their professional ethics and the ethos of their employers.

Concluding reflections

In considering different experiences of struggle, it is clear not all struggle is adversarial in the sense of involving some form of battle. Although some struggles reflect conflict, more frequently they relate to more mundane aspects of living or working with children who are different from most other children. Many struggles relating to the formal systems that comprise the special needs domain are not adversarial either, but relate to ways in which those services are organised or to the effects of changes in those systems.

The focus of this chapter is the 'normal' experience of struggle of parents of children with AS/HFA and the practitioners who work with them. Practitioners' experiences are limited to the workplace. They are aware that they are not always able to respond appropriately to

children with AS/HFA, on occasion due to lack of knowledge of the condition and at other times due to lack of resources and or because they are not convinced the response available within the setting is the most appropriate. For some practitioners, struggle also had a personal dimension. They recalled specific children or incidents and spoke of continuing feelings of guilt, shame and regret that they had not been able to address those children's needs appropriately.

The struggle for parents affected all areas of life. Initially, they have to recognise and accept their child's differences and then to manage the effect of those differences on themselves and on other family members. Further struggles are encountered when the child enters public spaces, in particular the school environment. The child's differences cannot be hidden as in the home and parents focus on damage limitation, protecting their identity and that of other family members and safeguarding social and cultural capital. For some parents, the risk to status and capital is greater than for others, as begins to be seen in the experience of some of the parents in this study, who had the highest accumulations of cultural capital, and had high status in other settings, but who found this of little value, at least initially, in their negotiations and seeking support in the special needs domain. This is discussed further in the next chapter.

A recurring theme in interviews with both parents and practitioners was that of dealing with the difficult behaviour exhibited by some children and young people with AS/HFA. These behavioural differences became a problem for parents, when the behaviour affected other family members adversely or when the child's behaviour outside the home attracted the attention of others. Parents, who were unused to being a focus of attention, found themselves out of their comfort zone, unsure how to act or respond as they faced public surveillance and their parenting skills were judged by strangers (Gray, 2002; Ryan, 2010). For practitioners, especially those in educational settings, inappropriate behaviour could present a health and safety issue, as other children had to be protected from violent outbursts. A further challenge for practitioners was determining when and how to respond differently to children with AS/HFA from typically developing children, particularly when determining punishments or consequences for bad behaviour.

I began this chapter by referring to Mills' differentiation of 'personal troubles' from 'public issues'. The struggles identified by both parents and practitioners can be considered personal troubles. Struggle reflects tensions experienced by the individual and those tensions may be experienced in the privacy of a personal space, as when a child's differences are first recognised, or may be found in public spaces, where a child's differences are opened to public gaze. Both parents and practitioners discuss struggle in terms of their personal experience, rather than in relation to policy, systems and governmental decisions.

'Personal troubles' are experienced in both personal spaces and in public places. As long as the problem is contained within the personal space, it remains private and is the property of the individual or the family. In the case of AS/HFA, a parent may be aware of their child developing differently from other children and may be confronting the implications of this difference, but choosing to do so within the confines of their own home, or other spaces they have some control over. Once the difference becomes evident in a public place, such as the train, the town centre, or the school playground, the 'personal trouble' ceases to be owned solely by the individual or the family. As the processes of public surveillance intervene, others also exercise control, whether or not the problem affects them directly.

In the next chapter I move from the everyday experiences of struggle for both parents and practitioners to considering the actions the actions taken by parents and practitioners when confronted by situations that lead to struggle, including situations where struggle might lead to fight. I focus on the social, cultural and material resources participants bring into the special needs domain and how these assets affect their use of agency and capital in practice.

Chapter Seven

Special Needs: Capital, Action and Advocacy

In the last chapter I referred briefly to the disjunction, or hysteresis effect, experienced by participants when encountering situations for which their previous life experiences had not prepared them. In this chapter, I explore various ways in which participants responded to challenging situations and how theses responses were affected by the resources participants brought with them into the special needs domain. As parents and practitioners engage in struggle, and as parents prepare for potential battles, they use their attributes in different ways, they accumulate and invest capital and their habitus is reshaped.

Just as parents and practitioners face different struggles according to their personal situation as well as the context in which they encounter those particular tensions, the participants in this study were differently equipped when they entered the special needs domain, by virtue of their training and previous life experiences. This chapter is divided into two main sections; in the first section I consider the resources participants bring to the 'field of play' (Bourdieu, 1985) and secondly, I explore the actions taken by participants to acquire new resources, in particular knowledge of AS/HFA and the special needs domain, and how they use their resources in practice. Parents and practitioners engage in interaction in what might be considered the boundary zone between the personal and public domains (Konkola et al., 2007) and may 'prepare for battle'. Figure 8 extends the diagram at the start of the previous chapter to show this new location.

	Private Space	Public Space	Outcome
Personal Domain	Personal Trouble *not requiring public (governmental) intervention*		Struggle
Interface of Personal and Public Domains			Preparation for Battle
Public Domain			

Figure 8 The interface of private and public domains

A key element in this discussion is how both parents and practitioners learn to play the game (Bourdieu & Wacquant, 1992) through learning its rules and language, coming to understand the discourses that encode the inequalities of power (Ranson et al., 2004) and becoming fluent not only in the language but in the nuances of the game (Matthews & Hastings, 2012).

The attributes participants bring to the field of play

In their study of parental interaction with schools, Vincent and Martin (2000) categorised parents as belonging to one of three groups dependent upon their level of interaction with the school. They then considered the social, cultural and material resources of the parents in each group and related these to the agency exercised by parents (Vincent, 2001; Vincent & Martin, 2002). My analysis is less complex, but recognises that parents and practitioners individually bring different resources into the special needs domain. Each has an individual habitus, formed through their accumulated life experiences, which has established their disposition as to how to act in different circumstances (Bourdieu, 1998, p. 8). They also each have a store of accumulated capital, both family and personal, including financial resources, social networks, cultural knowledge and disposition for learning (Bourdieu, 1998).

I divide both parents and practitioners into broad types according to their position on entering the special needs domain. These categories are neither definitive nor static as both parents and practitioners change through the experience of working with or parenting children with AS/HFA.

The parents are categorised as

- Those entering the domain with little or no prior knowledge of ASCs and few, if any transferrable skills relevant to the domain
- Those entering the special needs domain with some prior knowledge of ASCs, acquired through personal contact or training
- Those entering the domain, with or without prior knowledge of ASCs, but economic, social and cultural capital that enables access to further resources.

Similarly, the practitioners had varying knowledge of AS/HFA and of the special needs domain more generally. They are categorised as

- Practitioners who have little knowledge of ASCs or the special needs domain prior to taking up their post
- Generalist practitioners who have surface knowledge of the special needs domain/and or ASCs
- Specialist practitioners who have expert knowledge of the domain and ASCs gained through formal training, informal learning and experience

I introduced Bronfenbrenner's ecological system model in Chapter Two, drawing attention to the common heritage of Bronfenbrenner and Bourdieu in both being influenced, directly or indirectly, by the work of the mathematician and philosopher Cassirer. Bronfenbrenner's model can be depicted as a series of concentric circles, or the mesosystem can also be shown as the network of microsystems (Leonard, 2011), from which individuals derive their social capital. In this section of this chapter, I show a diagrammatic representation of the mesosystems for each of the groups of parents and practitioners. These diagrams represent the position of the parents in each group as they enter the special needs domain and of the practitioners at the time of the interview.

Parent with little relevant or transferrable cultural capital (Figure 9)

Five of the eleven parents interviewed belong to this group, which represents parents who may know a little about ASCs from general access to broadcast and print media, but have little or no knowledge of the special needs domain. Although they may have cultural capital acquired from education, training or experience, this may not be readily transferrable to the special needs domain. The primary microsystem for these parents is their family and friendship network and some may also be in employment, but neither of these sources of social capital contribute to the supply of accumulated capital relevant to the special needs domain.
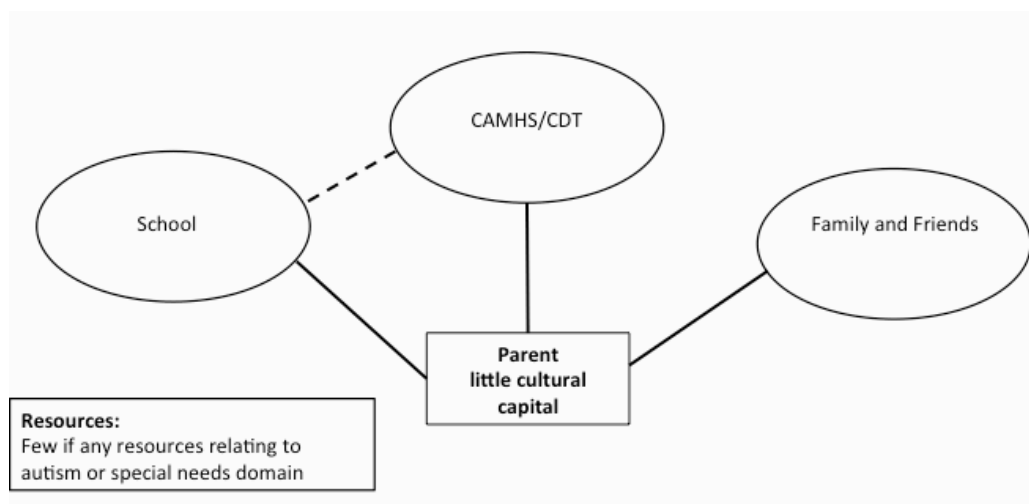
Figure 9 Mesosystem of parent with little or limited relevant or transferrable
cultural capital

As parents recognise differences in their child, they may consult child development manuals, or share their concerns with friends, but as discussed in Chapter Six, parents tend to focus on positive aspects of their child's development until their child's differences become problematic either within the family or the wider community. As the parent becomes aware of their child's differences, the school and the clinic become the primary sources of information and support.

In either case, the information provided to parents may be limited. Parents may also find their contribution to discussion relating to the child's support is restricted. In depending on practitioners for support and information, these parents are similar to the parents who formed the third group in Vincent and Martin's work on parental voice and agency, namely those who had least interaction with the school (Vincent & Martin, 2000, 2002), but unlike the parents described by Vincent and Martin, these parents acted to increase their understanding of both their child's condition and the special needs system more generally.

Some parents, like Angela, while initially resisting the suggestion that her son might be different, following diagnosis not only informed herself about autism but also used her increased cultural capital to ensure her friends and the parents of her son's friends were equally well informed:

> I gave that book to his friends and…there's another book that's fantastic…and I photocopied it and I gave it to his friends' parents.

Similarly, when Dominic received his diagnosis, Sally joined the National Autistic Society and equipped herself with cards, printed with a brief description of Asperger's Syndrome, that she could hand to people who reacted negatively to Dominic's behaviour in public.

Parents with relevant cultural capital (Figure 10)

Some parents had pre-existing knowledge of ASCs because members of their extended family had an autism diagnosis or because they had been involved in other ways with people on the spectrum, one parent having learned about autism as part of her professional training.
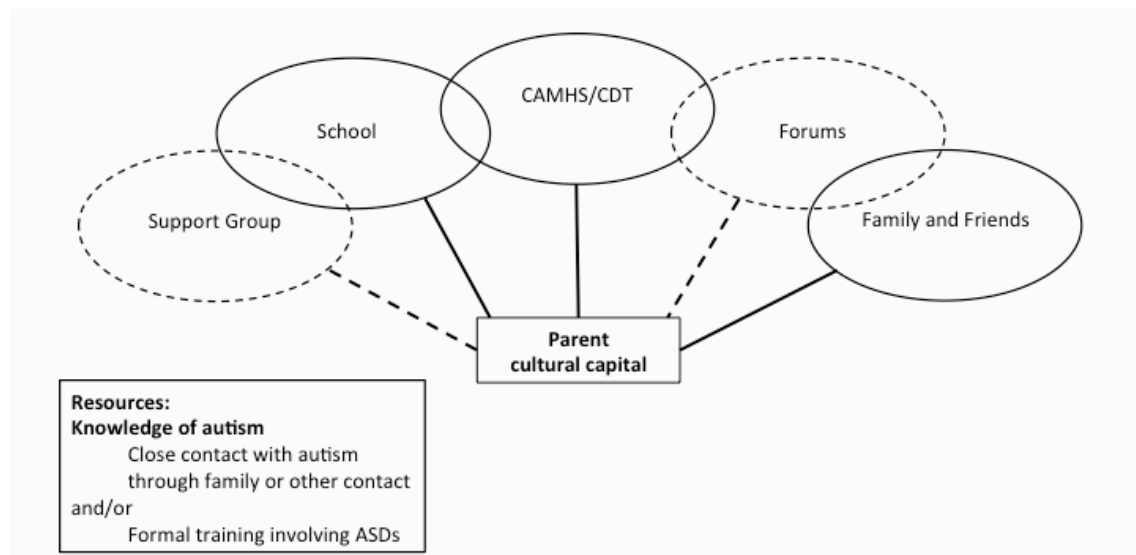

Figure 10 Mesosystem of parent with existing knowledge/experience of ASCs

There were just two parents in this study in this group, both of whom had experience of autism within their extended families and had relatives who were, or had been, involved in the care of people on the spectrum. One was a professional carer and had supported people with a range of different special needs including ASCs.

Carol realised Nathan might be on the spectrum before it was suggested assessment might be appropriate and focused on preparing him for everyday living. She did not find his diagnosis remarkable; it confirmed what she already knew. Penny, on the other hand, recognised differences in her child, but was resistant to these being formally assessed unless Harry would benefit in some way from a diagnostic label.

The primary source of support for both Carol and Penny was their existing social network, especially their extended families. Both availed themselves of support from other parents through parent support groups and online forums. Neither took any specific steps to increase their knowledge of either ASCs or the special needs system more generally, but both were aware this might be necessary should problems occur in future, and knew where they would go for such help and support. Of the parent participants in the study, these parents were the least proactive in seeking support for their children, but also appeared most accepting of their child's differences. This may reflect a lower anxiety about the child's condition in the light of previous experience of AS/HFA and might also reflect the knowledge of AS/HFA in the parents' networks, making it less necessary to turn to practitioners for additional support. Although Carol repeated the phrase "life is as hard as you are going to make it" several times during the interview when talking of coping with some of the challenges she faced with Nathan, this did not imply a lack of concern or interest, but an acceptance of Nathan's condition as being part of who he is.

Parents with transferrable cultural and social capital (Figure 11)

Some parents, while having little or no previous exposure to ASCs or the special needs system, had other experiences and contacts which they were able to use to inform themselves about autism and the various support systems and resources available within the special needs domain. There were five parents in this group.

These parents were all educated to at least first degree level and were employed, or had been employed, in professional roles. They used their existing skills and networks to gain an understanding of their children's differences and to argue for appropriate support and resources. Four of the parents had access to resources that enabled them to consult not only NHS practitioners, but to obtain assessments from medical and other practitioners in private practice. The primary way in which they differed from other parents was in their use of skills gained elsewhere to access and utilise information and in their awareness of how formal systems operate. These parents resembled the parents in Vincent and Martin's first group

(2000, 2002), who aimed to form good working relationships with practitioners, but were prepared to act in ways they perceived as most beneficial for their children, if necessary taking action counter to advice or preparing to battle on behalf of their child.
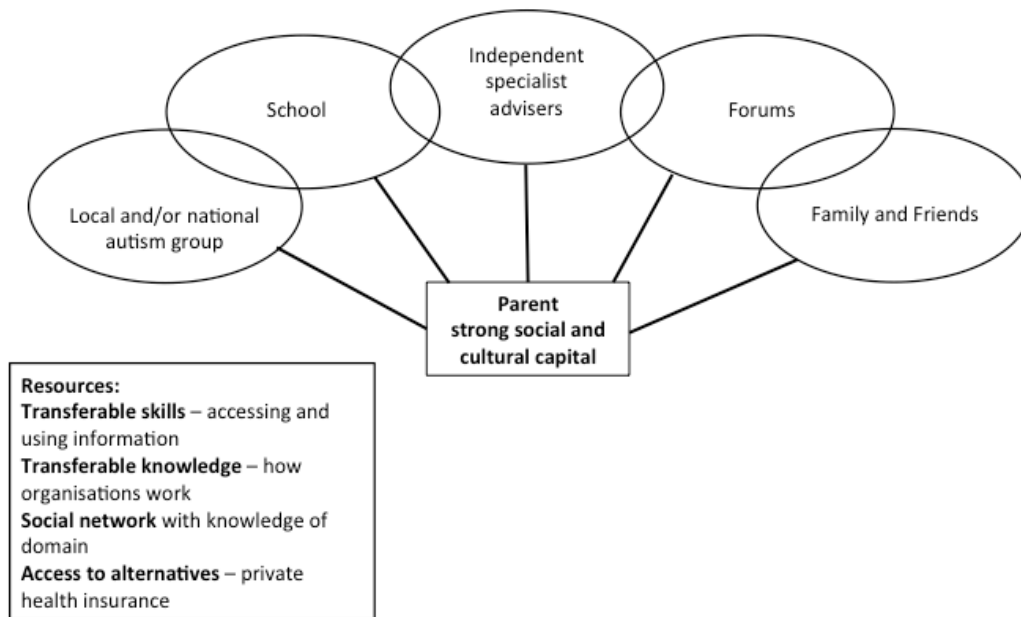
Figure 11 Mesosystem of parents with transferrable cultural or social capital

Naomi found she was "getting no help from the officials" so approached Paul's differences as she would a scientific investigation

> I was frantically looking at cross matches of potential symptoms.

At the same time, Naomi's husband, a lawyer, used his existing skills to understand the operation of the formal SEN system. Naomi later found she was giving practitioners information that she felt they should be providing.

Lynn was able to use her experience, gained as a social worker, to write reports and to ensure the involvement of informed practitioners from education, health and children's services in meetings where decisions were made about Sam. Unlike other parents, who were wary of social work involvement because of the child protection role of social workers, Lynn actively sought social work involvement in order to gain the support needed to obtain the residential placement she considered essential for Sam's wellbeing and education.

Jenny used teachers and others in her social network to access information about the working of the SEN system. Later, she invested in obtaining specialist advice, engaging the services of a paediatrician in private practice and a specialist solicitor, acknowledging this was not an option available to all parents and was not necessarily the only or best approach:

> You end up in a cycle where you're going down a particular route and you're spending and spending and at what point do you say, "Actually no, I can't do this any more." So we spent many, many thousands of pounds.

The parents in this group were not only better resourced in their accumulation of various forms of capital when they became aware of their children's differences, but they also increased their cultural capital as they developed knowledge of ASCs and the special needs system and also ensured they were connected to other parents and learning from their experiences. Once these parents had ensured the needs of their own children were appropriately addressed, they took an active role in support networks, sharing their knowledge and experience with other parents.

Practitioner with limited cultural capital (Figure 12)

Most practitioners have some training or experience prior to taking up their appointments in posts relevant to the special needs domain and AS/HFA, but some, primarily those in support roles, may have little or no prior experience of children with special needs of any sort. For such practitioners, their first experience of a child with an ASC may be both unexpected and difficult:

> There was a boy in Year 5 who had Aspergers. The very first knowledge that I had of that, he was actually sort of throwing chairs, and they had to evacuate the classroom.
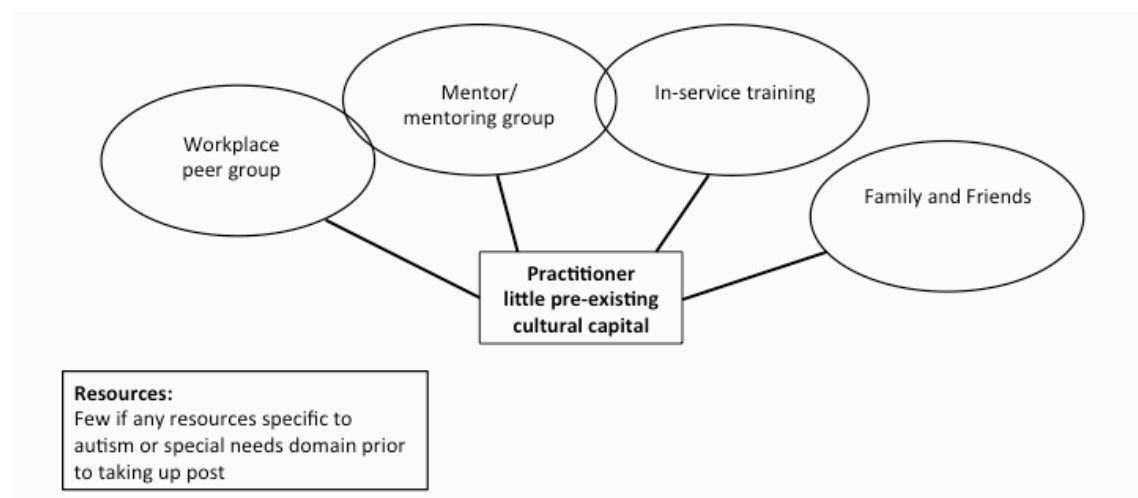

Figure 12 Mesosystem of practitioner with limited relevant or transferrable cultural capital

Such incidents may lead to in-service training opportunities or mentoring by a more senior member of staff, but some support arrangements are more informal.

Teaching staff are responsible for all the children in their classrooms, but very often support staff have the closest contact on a regular basis with children with special needs. Such staff may be recruited specifically to work with an identified child, sometimes as part of the provision made under a child's statement of SEN. Support staff do not only work with children in the classroom, but may be involved in providing support in unstructured time during the morning, afternoon and lunch breaks. LSAs also work with children on a one-to-one basis or in small groups, sometimes withdrawing a child or group of children from the classroom for additional support. Given the close involvement of these staff with children with special needs, it is arguable they need at least as much understanding of special needs as the teaching staff they work with. One experienced LSA observed that there can be a difficult balancing act in developing an appropriate relationship with a teacher:

> Sometimes a lot of teachers sometimes look to you as if you're going to get on with it with the child and I suppose with some children you can to an extent, but with some extreme children you can't. You've got to involve the teacher. And in some ways you are steering a teacher that might be young and not very experienced.

The observation is made in the SEN Green Paper (DfE, 2011) that some children with special needs do not receive sufficient input from qualified teaching staff, but are reliant on support staff to interpret teaching input. All the LSAs in this study spoke of themselves teaching children, some correcting themselves to emphasise their support role.

Practitioners with no previous training and experience were provided with in-service training or mentoring, but some expressed doubt about the value and relevance of the training to their role. One LSA had studied Open University modules to increase his knowledge of the special needs domain and another was supported by her employer to undertake an initial course in art therapy and was encouraged to use her skills classroom settings. None of the LSAs expressed any interest in developing their skills further through teacher training, but all showed evidence of developing a repertoire of skills and knowledge.

Generalist Practitioners (Figure 13)

The remaining practitioners were either generalists, such as teachers in mainstream schools, or specialists in various aspects of special needs, including AS/HFA. Three of the practitioners in this study could be described as generalists, namely an infant school teacher in a mainstream setting, a maths teacher in a specialist school and a medical student. Another teacher, who had previously been employed in a mainstream setting as a SENCo, did not regard herself as a specialist in AS/HFA, but was responsible for supporting pupils with

additional learning needs in a specialist setting, and described her specialist interest as children and young people who were gifted and talented.
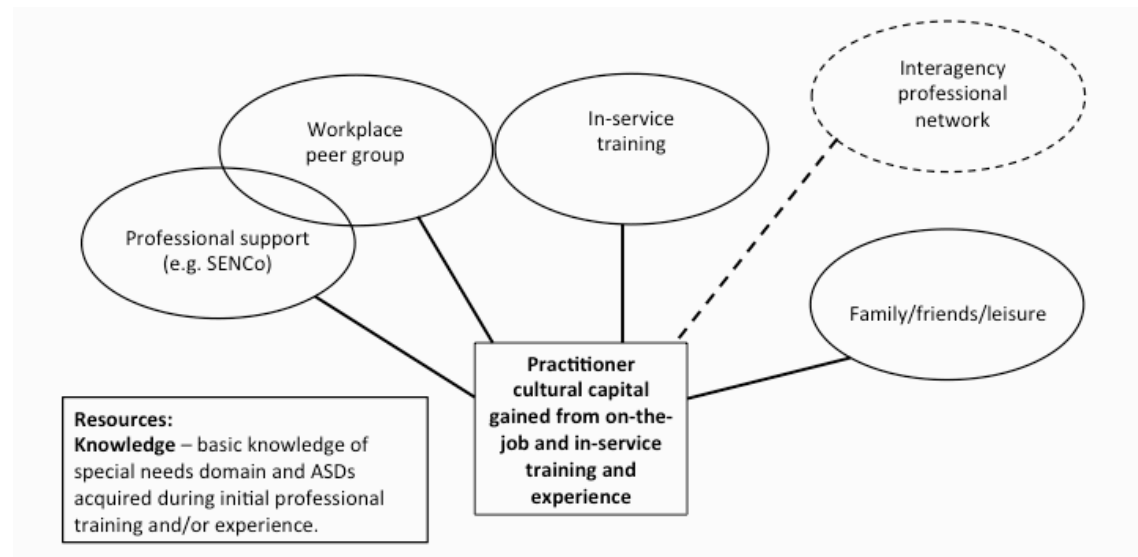
*Figure 13 Mesosystem of generalist practitioners with cultural capital
gained from professional training*

The teachers in this group all spoke of having attended in-service training courses and of receiving support from colleagues with specialist knowledge of AS/HFA, viewing the SENCo as having an important role in both understanding and communicating the operation of the SEN system to other members of staff and to parents. There was evidence of individuals taking action in order to improve their own understanding of AS/HFA beyond the information and training provided in their work settings. Mike had set up a reading list and was engaged in self-study and Kate had attended conferences in her own time and at her own expense in her locality. They were aware of practitioners from other agencies, but were unsure of their roles and there was no evidence of engaging in an interagency professional network.

Chris, a medical student, had a special interest in AS/HFA developed initially from babysitting for a family with a child on the autism spectrum. She was interested in developmental disorders and neurological conditions and had undertaken a neurological elective at another university, but there had been no mention of autism during the elective or in her first two years of medical training. At the time of the interview, she was placed in a CDC and had observed two autism diagnostic clinics. She viewed the absence of training content on neurological disorders as regrettable as medical practitioners, whatever branch of medicine they might practice, were likely to encounter people with social communication difficulties and behaviour problems and might not recognise these without appropriate knowledge and training.

Specialist Practitioners (Figure 14)

The specialist practitioners comprised those who had developed specialist knowledge in AS/HFA, either through their initial training and more specialist postgraduate courses or through experience and pursuing in-service training opportunities. Some of these practitioners were involved in decision making or making recommendations in respect of diagnosis or support provisions and were involved in the training and support of colleagues. It included a speech and language therapist, a SENCo, two psychologists, the principal of a specialist school and a consultant paediatrician. These practitioners were not only actively engaged in expanding their own knowledge and understanding of AS/HFA, but were involved in interagency collaboration and in providing consultancy and training to practitioners in generalist roles.
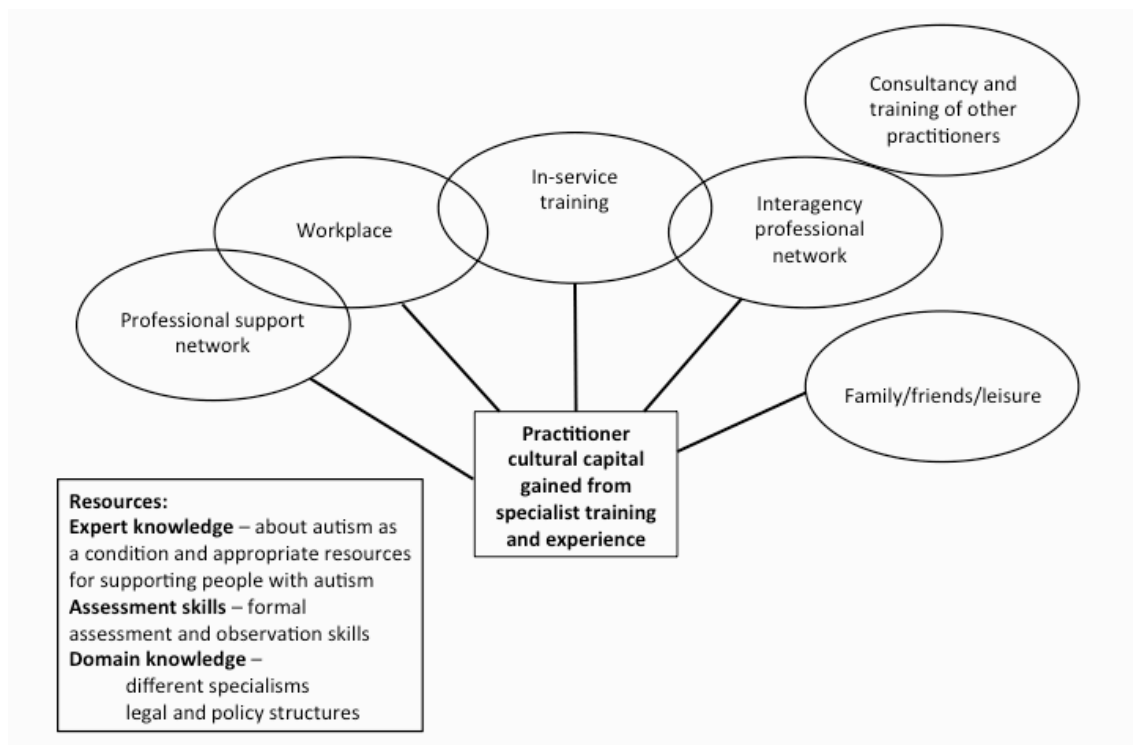
Figure 14 Mesosystem of practitioner with specialist training and/or experience

Discussion

Having considered the capital resources and potential for accumulating additional capital of the participants in this study, I now turn to participants' experiences of acquiring and using capital, focussing primarily on parental experiences. "Middle-class parents are skilled in using their social, economic and cultural capital to their advantage, especially within the

educational system" (Landeros, 2011, p. 248). A question permeating the next section of this chapter is whether those parents, who might be defined as most affluent in terms of social, cultural and economic capital, do in fact use this to advantage their children, or whether they may also be disadvantaged by sharing a professional identity with practitioners, sometimes "possessing higher educational or status levels" (Landeros, 2011, p. 249) than the practitioners responsible for the care and support of their children.

Accessing information – accumulating cultural capital

Information in the public domain

There is an increasing volume of information available relating to autism in the public domain. This takes the form of books and magazines, television and radio programmes, and a growing number of websites, online forums and support groups. Practitioners have access to professional publications and colleagues with specialist knowledge, as well as in-service training opportunities. Organisations, such as the NAS, have developed courses to provide information to both parents and practitioners, such as the 'Early Bird' course for the parents of recently diagnosed children. Although the amount of reliable information is increasing, Illingworth and Male (2011) report that there is also a large amount of less reliable and biased information available, especially online, some of which perpetuates the MMR debate or advises potentially dangerous therapies such as chelation. There is less information available to the general public about the SEN system and special needs resources, though again there are an increasing number of publications and online resources, including personal blogs.

Practitioner access to information and training

As discussed in Chapter Six, many participants in this study, both parents and practitioners identified gaps in their knowledge and understanding of AS/HFA and the special needs domain. Whereas it is unsurprising most parents had little or no awareness of the special needs domain, the SEN system or AS/HFA before becoming aware of their child's differences, it is more surprising that practitioners identified gaps in their knowledge and experience, especially as all the practitioners in this study either occupied specialist roles or were engaged in supporting children with special needs. The curriculum content relating to special needs on initial teaching courses has been increased in recent years, but this may not apply to other professional groups; the medical student included in this study reported that there had been no relevant content in her training. From the evidence of this study, it appears most practitioners learn about autism informally and experientially, mirroring findings about workplace learning in other domains (Boud & Solomon, 2003; Coffield, 2000; Eraut, 2007; Maaranen et al., 2008; Malcolm et al., 2003; Newton et al., 2009).

Special needs had formed an integral part of the initial training of some practitioners. Kerry first developed an interest in special needs doing voluntary work while still at school. She studied psychology as an undergraduate, writing a dissertation on autism, and went on to work as an LSA in a special school that sponsored her to train as a teacher under the Graduate Teaching Programme. Once qualified, Kerry worked in a local authority special school before moving to her current post in a local authority specialist school for children with autism. Apart from in-service training, Kerry has further developed her specialist knowledge through postgraduate study.

Joan, an educational psychologist, and Sarah, a clinical psychologist, also had first degrees in psychology, but their knowledge of autism at graduation was more limited, Joan commenting that during her undergraduate studies:

> Autism was used partly as a way of understanding typical development. You also studied atypical development.

Similarly, Sarah began to develop her understanding of autism during her postgraduate training, working in an organisation providing intensive behaviour interventions for children with autism, which necessitated Sarah working in people's homes where she got a "real feel for what it's like to live with obviously what's quite a disabled child with autism."

Other practitioners did not plan to work in special needs or with people with autism. John, a community paediatrician, did not encounter autism during his initial training. "Autism was not on the agenda. It didn't exist unless you were a highly specialist postgraduate." During his postgraduate studies, John was required to undertake a placement in community paediatrics, where he attended autism diagnostic clinics and found the condition "absolutely fascinating…it's all psychology and what's going on in the child's brain." John was also attracted by the intellectual challenge of arriving at a diagnosis without the assistance of blood tests and other aids.

Both Mary, a SENCo, and Brenda, a speech and language therapist, encountered autism at an early stage of their careers, when it was considered a rare condition, having received no prior training about the condition.

Some practitioners, who first encountered autism in their workplaces, explored ways of learning more about the condition for themselves. Kate first became aware of the condition in the early 1990s. She noticed a weekend conference was being held at her local university, sponsored by the local autism society, and arranged to attend at her own expense. Kate developed her knowledge further through reading, in-service training, and consultation with peers. Mike was engaging in a self-education programme in autism, which included using part of the interview to ask me how he might access materials in academic libraries.

More commonly, practitioners gained their knowledge of both autism and the special needs system from a mixture of exposure to children and young people with ASCs, in-service training, advice from peers, reading reports prepared by specialists, and contributing to annual reviews. In this, their experience was not dissimilar from that of parents, who initially learned about autism from engaging with their own children, information from practitioners, conversation with other parents and seeking information on the Internet. Some practitioners had less expertise of AS/HFA than parents. While some practitioners are able to take advantage of parental knowledge and expertise, others recognise their vulnerability and respond in ways that increase rather than minimise struggle.

Parental access to information and training

There was clear evidence of parents using their existing knowledge resources and skills in accessing information to acquire further knowledge in order to understand their children's conditions and the support systems available to them. Those parents with experience of higher education used the skills they already had in accessing, assessing and applying information. Naomi, who identified herself as a scientist, reasoned:

> If it's not happening at home in the same way then it must be something about the outside world that's doing it to him.

In the absence of a diagnosis, she turned to academic journals, looking for cross matches of symptoms. Jane did not anticipate a diagnosis for her son, but once she was told he had Asperger's syndrome, she joined the NAS, read biographies of people with the condition, and registered to study for a degree in psychology. Jenny spoke to friends and colleagues in her social network, with knowledge of the SEN system, who were able to advise her on action she could take to support her son. Lynn used her knowledge of information systems to access online forums and access information websites to learn more about her son's condition. This group of participants were among the best informed in this study in terms of their knowledge of both ASCs and the special needs domain, however these parents were amongst those who encountered the highest levels of difficulty in accessing what they considered appropriate support for their children, as discussed later in this chapter and in Chapter Eight.

Those parents with fewer reserves of cultural capital tended to use practitioners as their primary source of information about both their children's conditions and the special needs domain, and in particular the SEN system. Many authors have differentiated the relationship with practitioners experienced by middle-class parents and other parents (Gillies, 2005; Reay, 1998; Vincent, 2001), centring this discussion on the greater access of middle-class parents "to material resources and professional social networks" (Gazeley, 2012, p. 300). The evidence in this study suggests this is not necessarily a class bias, but a difference based on

prior knowledge and the habitus of the individual. Middle-class parents may be "less likely to place their trust in professionals" (Gazeley, 2012, p. 300) and to question more, but this is, at least initially, a factor of habitus, rather than class – and as those parents with less capital accumulate greater resources, often out of necessity, the differences between parents from different backgrounds diminishes.

The parents who were most reliant on practitioners for information spoke of receiving relatively little information from health service practitioners at the time of diagnosis, mirroring the findings of other research studies (Bromley et al., 2004; Cuckle & Bamford, 2000; Davis-Groves et al., 2007; Harpin, 2007; Keenan et al., 2010; Osborne & Reed, 2008; Whitaker, 2002). John, a community paediatrician, acknowledged information provision had been poor in the past, but his team was addressing this and had created an information pack for parents of newly diagnosed children. However, Sarah, a clinical psychologist, suggested that the absence of information also reflected diagnosis being viewed as the completion of the diagnostic team's task, and a time to discharge a child, rather than a diagnosis leading to additional support for the child. She suggested that not providing information was sometimes deliberate and a form of rationing access to services:

> For parents it's very complicated. The diagnosis doesn't mean anything at all in terms of what they should or should not be entitled to…Money is tight and they [the local authority and health services] like to ration it. Sometimes it's rationed by actually not giving out very much information.

Once a child was diagnosed, parents wanted to know how to support their child and what resources were available to assist them. In the absence of information from practitioners, some parents formed support groups or joined existing ones. Not all parents found such groups helpful, finding some cliquey and unwelcoming to newcomers. Mandell and Salzer (2007) found a mixed response among parents to attending support groups, with some evidence of greater attendance when a clinician recommended the group. Banach et al. (2010) suggested such groups were more successful if they met for a limited period and had a clear agenda. Parents in this study, whether or not they were members of a support group, spoke of sharing information with or offering informal support to other parents. Some had been approached by SENCos and asked to mentor the parents of a recently diagnosed child, and one had been appointed as an LSA on the basis of the knowledge she had acquired from her parenting experience.

The parents in this study worked hard to gain knowledge and information about the implications of their children's condition and the resources available to them, but there was evidence of some significant gaps in their knowledge, though these gaps were different for different parents. One such area related to the financial support available to parents of children with special needs. Whereas most parents were aware of and claiming DLA, one parent did not know of the benefit or her entitlement to it, and there was much less

awareness generally of entitlement to Carer's Allowance. Even when parents knew of their entitlement to DLA, they had been resistant to claiming. Carol was persuaded to claim by the school SENCo:

> I thought, I feel like a fraud – you know – I feel like a complete fraud, and I would not want to rob anybody that actually needed this more than I do. I said, "I felt – I'm thinking I'm coping in a sense I can do with very little. I'm coping and I'd hate to think I'm filling this all in and getting this money and I'm making someone else, who maybe needs it more than I do – doing them out of it." [The SENCo] said, "No, you're entitled to it. You go ahead and do that form." I said, "I will do. Honestly, I will." And then it got to the writing about your child and your worst days and their needs, and I thought, I don't want to put in about his potty training. It's like I'm a really crap mum…but I did.

The introduction of the Universal Benefit (HM Government, 2012b) currently is not planned to extend to DLA for children, but there is anecdotal evidence from postings to online forums that the level of the allowance is being reduced when a claim is renewed. Parenting a disabled child carries financial costs (Bennett, 2010) and many families with disabled children are considered as living in poverty (The Children's Society, 2011), but the increase in negative and pejorative language used to describe benefit claimants (Garthwaite, 2011) may result in parents of children with AS/HFA becoming even more reluctant to claim an allowance that they already doubt their entitlement to.

Discussion

Access to accurate and informed advice and information is a continuing necessity for parents. This information should encompass the resources available to support the child from health, education, social care, welfare benefits, and other sources as well as information about the child's special needs. It is not only parents who need access to such information, but practitioners need to be well-informed and able to advise parents where to obtain information, if they are not able to provide the information themselves. Both parents and practitioners require guidance in evaluating information, including acquiring greater digital literacy skills. Parents need to be aware that practitioners "may have a number of different and at times conflicting agendas to consider" (Gazeley, 2012, p. 303), which may influence the advice they offer. Overall the evidence from this study is that both practitioners and parents are accumulating cultural capital, in the form of knowledge and information about both AS/HFA and the support infrastructures, and sharing this cultural capital with others.

Use of agency and capital in the diagnostic process and beyond

Parental experiences of obtaining a diagnosis varied, as discussed in Chapter Six. The diagnostic process for children referred to the CDC shortly before or after starting school

tended to be a relatively straightforward process. There were exceptions, resulting in varying parental responses that demonstrate different use of agency and capital.

Using agency to obtain review of initial diagnosis

When Sally's son Dominic was assessed, she was told, "He's probably just going to be a bit eccentric." Sally was dissatisfied with this explanation. Following discussing her views with the SENCo, Sally kept a record of Dominic's unusual behaviours at home, and then arranged a further meeting with the clinical psychologist at the CDC. She was able to share her notes, together with examples of Dominic's obsessive writing and drawing. In the light of this further evidence, the clinical psychologist agreed that there was a need to review the diagnosis.

Sally had used her agency to collate additional data and request a further discussion. In providing additional evidence of Dominic's condition, Sally effectively became a member of the clinical team. Later, Sally was able to use the cultural capital she had acquired in recording information to make a request for a statutory assessment of SEN.

Using agency when there is no diagnosis forthcoming

It would appear that Paula's health visitor was aware that Aran might have special needs when he was a toddler, as a place was arranged for him at a special playgroup. These concerns were not shared with Paula, who assumed the placement was for her benefit, as she was finding it difficult to cope with Aran's behaviour at home. After starting school, a referral was made to CAMHS where Aran was diagnosed with ADHD. Paula attended regular review appointments, when she made the clinicians aware of her growing concerns about Aran, but she found she was telling the same story to successive medical staff and felt she was not being heard. Eventually, she saw the same doctor on more than one appointment, and it was suggested that Aran might be on the autism spectrum, but the doctor declined to recommend a formal assessment, telling Paula:

> He's being looked after here because of his ADHD diagnosis, I don't see any need for formally diagnosing him.

Paula was not satisfied, but continued to attend appointments and also spoke to the SENCo, who confirmed she also had observed autistic traits in Aran. Eventually CAMHS offered Aran a series of appointments with a clinical psychologist, who also recognised autistic traits and referred Aran for an autism assessment, which resulted in a diagnosis of Asperger's syndrome, the whole process from initial referral to eventual diagnosis taking several years.

Paula did not actively pursue a diagnosis, but exercised agency by accepting each appointment and therapeutic intervention that was offered, while continuing to express her concerns about Aran. She was well aware that the diagnostic label might have little or no

effect on how Aran was viewed or the support he would receive in school, but she felt that it was better to have an 'official' description of Aran's differences that he could use, should he need to, in order to access support and resources, both as he continues with his education and when he enters work. Although both ADHD and AS/HFA are contested diagnoses, further work is required on the relative benefits of differential diagnosis, not only while a child or young person is in education, but also in adult life.

Use of capital to access non-statutory services

Both Sally and Paula were amongst the parents with less cultural and social capital when they entered the special needs domain. Jenny, on the other hand, occupies a high status professional role and has accumulated social, cultural and economic capital that she was able to utilise in James's diagnostic journey as discussed in Chapter Six. Contrary to a diagnosis providing access to support services for James, there were further problems in school, which led Jenny to further exercise her agency in engaging a solicitor, specialising in special needs, who supported the family in preparing a SENDisT appeal, in order to obtain a statutory assessment of SEN and a statement for James. Jenny expressed surprise at the existence of such practitioners:

> I didn't realise it. The fact that there can be such a thing as a solicitor who specialises in getting statements for children with special needs – I mean that just seems so wrong to me. But we felt that while things had gone so badly wrong for us so far, that we needed to do everything we could to make sure James was getting support.

Having engaged the support of a solicitor, Jenny then found she was caught in an expensive cycle of investing in additional assessments and reports:

> The first thing that the solicitor said to us was…"You're going to have to have [the reports] all done again…You're probably going to have to go to Tribunal, so you're going to have to have these assessments…" That started us up the next round of chasing around the country getting all those reports done and that took several months.

A further assessment, undertaken during the process of obtaining additional reports, suggested that James had Asperger's syndrome in addition to the already diagnosed ADHD and ODD:

> [The solicitor] said to me, "It's absolutely critical that if there's the slightest thought that he might be on the autistic spectrum that that is reflected in his statement, because it will mean that he will be able to get support that he needs and his statement will be more accurate." So there were several strands of things running along in parallel during this period.

Jenny acknowledged that engaging a solicitor incurred costs that many families would be unable to meet. Further, having engaged a solicitor, additional costs were involved in

obtaining further reports and briefing a barrister in preparation for a Tribunal hearing, which never happened, as the local authority:

> Capitulated the day before the Tribunal. It really didn't occur to me that local authorities would put the parents of disabled children through something like that. You have to pay the barrister, the solicitor, the expert witnesses – and you know if they cancel the day before, you still have to pay them. We had the costs of thousands of pounds…And the solicitor kept saying to us, "Well in all probability they're going to give in" Which they did the day before [the Tribunal hearing]…But if it hadn't been for the solicitor, we would have given in long before and just accepted a statement that probably didn't reflect [James's] needs. But the solicitor was very, very insistent.

McKeever and Miller (2004) suggest that such capital investment has more than one function; in addition to procuring expert advice, it protects parental capital and social status and potentially protects the child's position in the future – a perspective supported by Nind (2008) in her case studies of grandmothers of children with special needs.

Response of practitioners in statutory services to 'paid for' assessments

Using private medical and legal services may present difficulties in interactions with practitioners based in the NHS or local authority. A diagnosis from a private practitioner may be regarded as suspect. The local authority educational psychologist involved in Sam's statutory assessment of SEN asked Lynn if the diagnosing clinician was qualified to make a diagnosis. Later, when Sam was re-assessed by the CAMHS Tier 3/4[12] team and his diagnoses confirmed, the consultant commented that this diagnosis came with the NHS stamp of approval. Naomi was told by a NHS speech and language therapist that she:

> …had been a very naughty girl to have gone off and got [Paul] diagnosed via medical specialists and then come back into the system, "Because actually it's very unusual." As though somehow this made the diagnosis suspicious as [she said] "It's very unusual not to have gone through the speech and language for Aspergers."

Parents paying for second opinions, private reports or legal advice is a contentious area. Joan, an educational psychologist expressed her concern:

> You sometimes feel that people who can afford to take the County to Tribunal and pay for reports and lawyers and so on will get what they want in the end, because they will spend so much money on it that it's not really worth in the end the County fighting it…There are some times where you think, "Really this is not how the system was set up. This can't

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[12] Mental health services for children and young people are organised in a 4 tier system: Tier 1 services focus on less severe mental health conditions and are provided by GPs, health visitors, school nurses, teachers, social workers, youth justice workers, and voluntary agencies; Tier 2 services address more serious and complex conditions and are provided by community mental health nurses, psychologists, and counsellors; Tier 3 services are for children and young people with severe, complex and persistent mental health conditions and are provided by a multidisciplinary team; and Tier 4 provides specialist services for children and young people with the most serious problems and are usually provided in specialist units.
http://www.nhs.uk/NHSEngland/AboutNHSservices/mentalhealthservices/Pages/Availableservices.aspx (accessed 08/09/2012).

be a good use of people's time and resources, and kind of can't have been what it was for in the first place." So there's definitely times when you think the current system's being abused to be honest by people who've got the money to do it, because it's not the vulnerable people who go to tribunal.

Ashall observed "a person's level of education, the cultural capital that they possess, combined with the value of the networks on which it is possible for them to draw and the amount of economic capital at their disposal, gives a person certain advantages and disadvantages" (2004, p. 23). Amongst the participants in this study, it was generally those parents who were best connected, most highly educated and who had most access to economic capital that chose to turn to the private sector. The exception to this is Linda, who explored the possibility of paying for legal support, but chose to argue David's case herself, when she realised the cost involved. This contrasts with Lynn, who decided to argue the case herself when she realised her solicitor was using material she had drafted in his representations to the local authority for which he was charging her fees. Linda's experiences are explored further in Chapter Eight.

School level conflict – power, agency and 'having a feel for the game'

All study participants spoke of situations that could be described as struggle, but two drew attention to specific experiences that went beyond examples of everyday struggle in which parents found themselves engaged in a confrontation with a senior member of school staff. In each instance, the situation can be viewed from the Bourdieusian perspective of having a 'feel' for the game and knowing the rules of the game.

Manipulating the rules of the game

Linda's son David was statemented when in infant school and reached Year Six of junior school with only minor difficulties. It was traditional for Year Six children to participate in a residential experience. David's parents knew this might be challenging for both David and the school, and made preparations to enable David to participate, if he wished to, including arranging for Linda to take annual leave from her work so she could accompany David. Initially, this arrangement appeared acceptable; the booking form and deposit were accepted by the school, and Linda confirmed with David's class teacher, and later with the SENCo, that they wished David to participate in the activity and that she was willing to accompany him. No indication was given that David's participation in the activity was problematic. However, Linda was then asked to attend a meeting with the headteacher:

> Everything I said, [the headteacher] put another obstacle in the way. There was no way they were going to take him, but she couldn't say that of course because of inclusion...There was no way she was going to give

in and I really hated her because she made me cry in that meeting and I don't like – because I was so angry and frustrated. I wanted to poke her eyes out. And I really hated her. And everything I said, she just put up another obstacle. I mean, she knew her game, that woman and she knew how to word things, and how to get her own way…I'd never been in that position before where I had to fight for my child to do what he should have had a right to do. And she got the better of me because in the end, I could have kicked myself. Well I did kick myself quite a lot when I came out of there, because I got so angry. In the end I said, "OK, fine." I said, "I'll take him out of school and I'll take him away myself."…Looking back now, it's easy for me to say that I should have done something about it. I should have been stronger. But I wasn't. But I was just, I was mentally and physically exhausted.

Linda uses Bourdieusian language in her account of this encounter, in saying the headteacher "knew her game", implying a sense of awareness that such encounters are choreographed and require each participant to know the rules. Linda had prepared for the encounter by familiarising herself with disability discrimination legislation and proposing to accompany David, so as to enable the school to make reasonable accommodations to include David in the activity. She knew the school would carry out a risk assessment, but she did not anticipate the school identifying risks that were so unlikely to happen that the assessment effectively became a tool to exclude David from the activity. By using the risk assessment to subvert the spirit of the disability discrimination legislation, the headteacher was acting in a similar way to the psychotherapists in Kirschner and Lachicotte's study (2001), who resisted the imposition of rules, they perceived as contrary to their professional ethos, in the introduction of a case management system. This may also reflect the different agendas practitioners may be working to simultaneously as mentioned above, in this case ensuring a successful experience for the majority of children in the year group, though Reid (2011) suggests it is not unusual for children with AS/HFA to be excluded from such activities.

Linda later learned another Year Six pupil, with similar difficulties to David, was permitted to attend the residential activity accompanied by his father, suggesting that either the other child's parent was better equipped to 'play the game', or that there was a more complex game in play than initially evident. Linda used what agency she had to withdraw herself and her son from the situation and to make alternative arrangements, in this respect mirroring the use of agency of the parents in Vincent and Martin's 'high' group (Vincent & Martin, 2000, 2002). In terms of the effect on Linda, the incident, while distressing, changed her from somebody who trusted the school and expected to cooperate with practitioners to somebody who was prepared to fight for her son's rights, as evidenced in Chapter Eight.

Hysteresis effect – coping with the unanticipated

Jenny holds a senior position in her profession and is the mother of three children. Prior to her youngest son starting school, Jenny had little awareness of special needs or the SEN

system and her contact with the local primary school was limited to parent consultation evenings and events to which parents were invited. As already discussed, despite her lack of knowledge of special needs, Jenny is well connected and used her social, cultural and economic resources to access support for James.

James found it difficult to fit in with other children when he started school. He was violent and aggressive to other children and to adults, especially Jenny:

> I was black and blue. He was very violent towards me.

Jenny's relationship with the school changed, as she was no longer viewed as a high status parent, a capital asset, who might attract similar parents to the school, but instead became a parent who was invited to discuss her son's difficult behaviour with school staff. Jenny experienced these conversations as unhelpful, with no discussion of strategies that might assist James and no suggestion that he might have special needs. Jenny used her social network, to learn that schools have SENCos and that the SENCo might be able to assist in accessing support strategies for James. Although Jenny knew the rules and topography of her own professional domain, she found dealing with the school domain confusing, and had little in her experience that prepared her for navigating both the school system and the special needs system more generally. The sense of being on unfamiliar territory, such as Jenny experienced in the school setting, is an example of the phenomena Bourdieu describes as 'hysteresis', when a social agent's dispositions do not equip them for the *field* environment they encounter, and there is a need for the habitus to adjust to the new circumstances.

As a result of contacting the SENCo, an educational psychological observation and referral to CAMHS were arranged, but communication failures meant that Jenny was not informed of the outcome of the observation, despite asking for feedback, and the referral to CAMHS was delayed due to paperwork going astray. More troublingly, Jenny experienced a negative attitude from members of school staff:

> Every time I would say anything, there were these sort of conflicted opinions about me going on. I remember sitting in meetings with that headteacher where she would actually smirk if anybody said anything about me which could be construed in any kind of a negative way…She would actually sit and smirk to herself. I can still remember that. I don't think I will ever really forget it. [I remember] thinking, "I'm the parent of a child who is in great difficulties. Surely, if we're in need of anything, it's support and sympathy, not hostility and aggression and putting us down."

Jenny attended a number of meetings, including some with members of the school governing body. At one such meeting, convened to hear an appeal against James's exclusion from school, those present were given paperwork that included personal information about Jenny and her husband, not relevant to the discussion. Jenny, supported by a local authority representative present at the meeting, raised concerns about confidential material being

circulated without permission, but received no apology, and the offending paperwork was not withdrawn. Jenny felt she was fighting the headteacher and the school system in order to have James's needs addressed, to safeguard his school place and to protect her own privacy and identity.

James returned to school, but Jenny's sense of being involved in a fight with the headteacher continued:

> Within two weeks of [James] getting back to school full-time, I came to pick him up from his childminder's house and discovered that what had happened that day was that he'd been in school [and] there had been some kind of altercation. They'd taken him to the headteacher's office…They didn't try and contact me…At the end of this two and a half hours of being in the headteacher's office…he had trashed the room…They didn't try and get hold of me.

During the interview, Jenny gave further detail of this incident, which if accurate could be construed as abusive behaviour on the part of the school. Jenny considered the school manipulated a situation to show James's behaviour in the worst possible light. Whether or not there was a personal element to this struggle, Jenny experienced the situation as the headteacher using her position to act inappropriately in ways that were detrimental and led to a complete breakdown of trust. Jenny decided the only action available to her was to withdraw James from the school and lodge a formal complaint with the local authority.

Discussion

This confrontation can be viewed from different perspectives and the headteacher or others might give a different account from that provided by Jenny. Whatever the veracity of the account, James is a child with complex difficulties attending a school that may have had little previous experience of children with complex special needs. A child with behavioural difficulties attending a school located in an area populated by high status families might be viewed as deterring parents from choosing to send their children to that school, reducing the status of the school. Alternatively the account may be read as demonstrating the naivety of a headteacher and SENCo, who were relatively inexperienced in dealing with complex special needs. A further interpretation is that of a struggle between individuals with power and status in their own fields, but a different level of familiarity with the rules of the special needs field. Even when a school encourages partnership and collaboration with parents, there is a lack of equality between parents and senior members of school staff (Bendelow & Brady, 2002; Todd, 2000; Todd & Higgins, 1998; Todd & Jones, 2003). A further possible analysis is the one offered by Jenny, that the headteacher was threatened by a high status parent with higher professional status than herself, who, rather than seeking ways to cooperate, became defensive and sought ways to undermine Jenny and her position. If the headteacher belonged to the middle group of practitioners, as identified at the start of this chapter, and

had relatively little experience of AS/HFA and associated behavioural problems, this offers a rational explanation for the events described by Jenny.

The lack of equality between parents and school leaders reflects not only the actual position of the headteacher within the school community, but may reflect the remnants of parents' experiences as pupils in their own youth (Hanafin & Lynch, 2002; McKeever & Miller, 2004; O'Donoghue, 2012). A parent may view the headteacher, not as another adult, but might attribute the same status to them as to the headteacher of their own schooldays, placing them in a position of power rather than partnership. This induces an internal conflict in the parent between their habitus, as shaped by life experience, and the disposition of their younger self.

The immediate effect of the confrontation on the parent was to reduce her trust in the headteacher and in the operation of the special needs system and the supporting legislation:

> It was the first of a whole series of things that happened that made me realise that as a parent you're totally disempowered in the process [and] that professionals share information with each other, which they don't necessarily share with a parent, and so [as a parent] you haven't got access to full information. I also found out that there are systems out there that people actively don't want you to know how they work because it's in their interests for you not to know. If you know, then you'll ask for things you're entitled to and if everybody asked for what they are entitled to the system would break down because they couldn't afford it.

Just as "parents in school exclusion processes are situated between the child and the professional" (Gazeley, 2012, p. 303), the same applies to parents of children with AS/HFA, and in both cases when difficulties arise, the space occupied by parents is an emotional one. The position of a parent in a school setting is largely determined by the school (Gazeley, 2012; Landeros, 2011; Vincent, 2001; Vincent & Martin, 2000, 2002). When difficulties arise, parents no longer perceived themselves as acting in partnership with the school, but as engaged in a battle. In order to fight effectively, parents accumulate additional capital by equipping themselves with knowledge of the SEN system and its operation. The hysteresis effect, which parents experience as not knowing the rules of the game and feeling 'wrong-footed', leads to fundamental changes in the habitus of the parents and changes their perceptions of the special needs field and practitioners.

Activism and advocacy

Whereas many of the actions undertaken by parents relate to their own children, there are also actions that extend beyond the individual. Sousa (2011) and Silverman (2012) write of the actions parents take to support their own children and to challenge the support offered more generally to children with ASCs, identifying a change from the 1960s description of 'refrigerator mother' to 'warrior-hero'. The parents discussed by Sousa and Silverman had

engaged in projects, which made major differences to the treatment of people with autism. In this study, there were many examples of smaller acts of activism and advocacy that make a difference and reveal the agentic actions of parents and others.

Angela and Sally both hand NAS cards to strangers who react negatively to their sons' behaviour in public places. These cards offer a brief description of autism. These parents viewed the distribution of the cards an act of public education. Angela also spoke of encouraging the parents of her son's friends to read information about autism and to share storybooks about autism with their children. Underlying these actions is a belief that if people in general know more about AS/HFA and how it is experienced in everyday life, people with these conditions will experience less stigmatisation and their behavioural diversity will become more acceptable. This can be viewed as examples of enacting movement towards a social model perception of AS/HFA, as members of the general public change their attitudes and reduce their disabling behaviours.

Two of the parents in the study were facilitating parent support groups, providing opportunities for parents to share information and resources and to discuss strategies for dealing with the difficulties they confronted personally with their children and with obtaining appropriate support. The establishment of such groups was supported by practitioners, even when they knew this would place additional demands on the service they offered. Mary, a SENCo, had made a meeting place available to parents in the school where she worked. John, a community paediatrician, visited parent groups established in his locality and provided information about the groups to parents of newly diagnosed children. Both the groups represented in this study had made contacts with their local newspapers, resulting in news items being published that drew public attention to aspects of autism, again with the aim of educating and changing attitudes.

It is not always appropriate for practitioners or parents to make direct representations to public authorities in the face of inadequate services. Many of the parents and practitioners in this study are individual members of the NAS and are able to make their concerns known through this organisation. In one initiative I became aware of through an online forum, representatives of a NAS local branch, supported by the national organisation, met several times over the course of a year with commissioning officers and clinicians from CAMHS in order to make the case for autism-appropriate services in their region. These discussions provided opportunities to share examples of both good and inappropriate practice and led to the creation of new mental health worker posts to liaise with local schools. Although the NAS branch was not claiming to have made significant changes, it had been able to act on behalf of both parents and practitioners to raise awareness of the need for ASC-specific knowledge and services, and had identified a potential willingness to provide some differentiated services. In a private communication with the NAS branch officer, she said that an additional

outcome of this initiative had been the establishment, by clinicians, of meetings for parents post-diagnosis, with the potential for these parents to form ongoing support groups.

Not all parents would describe their actions as activism or advocacy, but there was also evidence in this study of parents using their knowledge and experience to support other parents and children. Two parents were employed as LSAs, supporting children with ASCs, one having been appointed on the basis of her experience with her own child. Another parent had undertaken a research project on behalf of her local NAS branch. Two parents were undertaking postgraduate study in autism related areas. All the parents spoke of the support they had been able to offer to other parents who were struggling to find their way through the special needs system or obtain appropriate support for their own children.

Concluding reflections

This chapter has focused how parents change as a result of their involvement in negotiating the special needs field. Whereas some parents may choose to adopt and parent a child with special needs, birth parents may only become aware that their child has special needs some time after the child is born and vary in how well equipped they are to address the challenges of parenting a child who is different. Some parents have life experiences that have better prepared them for parenting a child with AS/HFA than other parents, in that they have knowledge, skills and other resources they can utilise. Practitioners also vary in their experience and knowledge of AS/HFA. Both parents and practitioners share a common task of acquiring cultural capital, in the form of knowledge and information about autism and the operation of the special needs domain. Although there is a tendency for the knowledge of practitioners to be privileged over that of parents (Elsworth, 2003; Fleischmann, 2005; Todd & Higgins, 1998), both parents and practitioners acquire their knowledge of AS/HFA in very similar ways, through formal training and informal learning, with most learning being work-based. Parents use their knowledge firstly to benefit their own children and later support and share information with other parents facing similar challenges.

Parents mobilise their capital resources, some spending large sums of money, some using their social networks and some building on existing knowledge, in order to ensure their children's needs are appropriately addressed. Having an accumulation of capital is not necessarily beneficial to parents in obviating struggle. It appears higher status parents, who are able to exercise choice and agency in their engagement with practitioners, may be viewed as a threat by less well endowed practitioners who may respond to such parents by protecting their own identity and position, sometimes at the expense of the child.

It cannot be assumed parents and practitioners share common goals. Parents primarily address the needs of their own children, whereas practitioners are cognisant of the needs of

all children and of resource constraints and other factors that limit responses. This may require practitioners to find ways of balancing conflicting agendas, or to engage in tactics, or games playing, in ways that can be experienced negatively by parents (Gazeley, 2012). Parents may engage in a struggle on behalf of their child and, in the last resort, exercise their agency by removing their child, and themselves, from a situation they view as insoluble. Such actions challenge the predisposition of parents to assume they are working together with practitioners for the wellbeing of their child. This disturbance, or hysteresis effect, results in changes in the habitus of parents, and has the potential to create a vicious circle where parents anticipate further difficulties and equip themselves with additional resources in readiness for future 'battles'.

Chapter Eight

From 'Struggle' to 'Fight'

In Chapter Six, I proposed Mills' (1959) differentiation of 'personal troubles' and 'public issues' provided a framework for exploring the everyday struggles of those who work with or parent children and young people with AS/HFA. Everyday struggles were identified as 'personal troubles' that can be experienced in both personal and public spaces. When the SEN Green Paper (DfE, 2011) describes the SEN system as adversarial, it refers implicitly, if not explicitly, to the 'public' fight some parents engage in with local authorities in order to 'win' appropriate support and resources for their children. It is this fight that is reflected in the press report of the encounter between David Cameron, leader of the Conservative Party and father of a disabled child, and Jonathan Bartley, father of a child with spina bifida and a campaigner on social policy issues including disability rights, during the 2010 General Election campaign. When Bartley challenged some of the policies relating to SEN outlined in the Conservative election manifesto, Cameron responded: "You didn't get what you wanted. I didn't get what I wanted. We both had to fight".[13] It is noteworthy that Bartley and Cameron differed in their views on the educational provision that they considered most appropriate for their sons, both of whom had SEN. The provisions fought over are those provided by the State as a public response to a 'public issue', and are provided by education, health and social care services. Parents may make recourse to an appeals system (Runswick-Cole, 2007a, 2007b) but, as was evident in Jenny's account as related in Chapter Seven, there is a cost involved in engaging with statutory service providers even when the argument is resolved before reaching Tribunal.

In this chapter I use the phrase 'system failure' to describe circumstances where the public response to a problematic situation fails, in some way, to address the problem appropriately, or in a timely manner. I focus on accounts given by parents of situations where elements of system failure were present. The accounts concern school exclusion, child protection and mental health. In each case there is a 'public issue' and a public response but the problem situation is also experienced as a 'personal trouble'. The accounts demonstrate that a 'personal trouble' may be exacerbated by an insensitive, inappropriate or untimely public response. The responses to these situations do not only affect the child with AS/HFA at the time of the incident, but impinge on their family, and may have a further impact on the child as they move into adulthood. A further characteristic of each of these accounts is that although the issue is responded to, the response reveals a lack of agency on the part of both practitioners and parents.

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[13] These words are not used in the written report but can be heard in the video clip on the BBC website http://www.bbc.co.uk/news/10088172

Figure 15 extends the diagrams presented at the start of the two preceding chapters to reflect the argument developed in this chapter. Parents experience all problems relating to their child with AS/HFA as 'personal troubles'. Those problems not requiring public intervention are identified as everyday struggle. Some problems take place at the interface of personal and public domains, and while not being identified as fight, may lead parents to take action to increase their social and cultural capital in preparation for future difficult encounters, recognising they may need to 'fight' for their child's needs to be appropriately addressed. Problems that enter the public domain require a public response. If the public response is perceived as inadequate in some way, struggle turns to fight, and that fight may or may not be conducted in a public space. Even though the problem is responded to with a public response, it continues to be a personal trouble for the parents involved, and the public response may exacerbate the personal trouble.

	Private Space	Public Space	Outcome
Personal Domain	**Personal Trouble** *not requiring public (governmental) intervention*		**Struggle**
Interface of Personal and Public Domains			**Preparation for Battle**
Public Domain	**Public Issue experienced as Personal Trouble** *requiring public (governmental) intervention*		**Fight**

Figure 15 Locating 'public issues' and 'personal troubles'

Before turning to the participants accounts, I first consider the meaning participants attribute to system failure.

System failure

Study participants referred to 'failure' when discussing perceived faults and problem areas in the formal and informal systems comprising the special needs domain and also in relation to the experiences of individual children. Both parents and practitioners speak of 'system failure'. Parents tend to focus on the needs of their own child, especially when they consider these are being ignored. Practitioners, while cognisant of parents' concerns, may be aware of the bigger picture and focus on addressing the needs of all children within their remit. Practitioners are also more aware of budgetary and other constraints and potential impact on other children of the resource implications of meeting the needs of one child.

Sarah, a clinical psychologist, pointed out that one way in which ASCs vary from many other types of special need is the lack of a standard package of resources appropriate to all children on the spectrum:

> For children with autism, they're always individuals. They can be extremely able and extremely disabled at the same time. Enabling them to make the most of themselves but supporting the disability side of it can be incredibly complex.

Even when the appropriate intervention is identified, it may not be available. Mary, a SENCo, had previously provided respite care:

> Social Services are just completely inundated…Respite has not improved one iota since when I used to do respite. In fact, I think it's probably got worse… It's just frustrating…The holidays I just think are nightmare time. I wish there was more out there…People don't know that these families need respite. They know about kids in wheelchairs. They know about kids in special schools. They don't know about autistic children and they don't realise the drain on the families.

Parents and practitioners both speak of children having to fail before their needs are addressed, sometimes correcting themselves and saying that the system has to fail the child before there is momentum to act. Ruth, an LSA in a specialist residential school, spoke of many of the boys attending residential school assessment having failed in mainstream, some being permanently excluded. Mary, an infant school SENCo, commented:

> They've got to fail before you can get further. And you think, no that shouldn't be what education's about.

Joan, an educational psychologist, spoke of placements breaking down and the need to develop strategies that avoided children "falling through the safety net", identifying also a lack of trust on the part of parents that provisions that were made or offered addressed the child's best interests, saying this was more prevalent in secondary schools:

> How do we help secondary schools talk to parents so that they feel that they can come in and share concerns, and that any concerns [experienced in school] will be fed back to them immediately, rather than waiting for six weeks until it gets to some sort of horrible crisis?

Sarah, a clinical psychologist, spoke of failure in the context of the decision of whether or not to make a statutory assessment of SEN and write a statement:

> They have to multiply fail before they get to the stage of getting a statement, which I think is horrible. We'll put them on School Action and then School Action Plus and then they'll sit for quite a long time. There has to be a lot of evidence of them failing at that before they get what they actually need.

John, a community paediatrician, gave examples of two children where the system had broken down, but in neither case was this predictable when the child was diagnosed or at subsequent reviews:

> I've had a boy at one of our local schools…He had done reasonably well until about Year 3/Year 4. I think in that year he probably had a teacher who was less autism aware in the way she managed things…He came back after the autumn half-term holiday and became unmanageable…He was permanently excluded and went to the Pupil Referral Unit. That didn't work…He has ended up going to a very expensive placement in a school for behaviour problems.

> I've had another child who pre-school we diagnosed with very borderline Asperger's…When we made the diagnosis, we said, "He's going to do really well. He's got the symptoms but they're not having any impact." Within six months to a year of starting at school, he had a Teaching Assistant who had used ABA [Applied Behaviour Analysis] with another child and thought this was the answer to all autistic children. Applied it to this child and it was disastrous. He was out of school completely for probably a year.

In the case of the first child, John hypothesised the combination of a more demanding curriculum and a less autism-aware teacher may have triggered the problem, and in the second case, the inappropriate ABA regime, but in neither situation was the outcome predictable at the time of diagnosis.

Joan, an educational psychologist, and Sarah, a clinical psychologist, both identified transfer to secondary school as a time when children might begin to have difficulties after coping well in primary school. John, a community paediatrician, countered this, suggesting parents are very anxious about the transfer to secondary, but children can find the secondary environment more structured and do well there.

A further sign of system failure, suggested by Joan, an educational psychologist, might be a parental decision to home-school. She raised concerns about the quality of the education a child might receive under these circumstances and the potential longer term consequences in managing everyday life and social situations if the child was not exposed to the social environment offered by a school setting.

Practitioners agreed it was more appropriate to describe the system as failing the child, rather than the child having failed.

School exclusion

Relatively few children are permanently excluded from school, but the numbers of children with SEN subjected to fixed term or permanent exclusion are of concern. The Lamb Inquiry indicated:

> About 70% of permanent exclusions are of children with SEN. Locally, rates of permanent exclusions of children with SEN vary between 43% and 92% of all permanent exclusions in that authority (2009, p. 52).

According to the Ofsted Review of SEN and disability:

> Pupils identified with special educational needs (both with and without statements) are over eight times more likely to be permanently excluded than pupils without special educational needs (Ofsted, 2010, p. 51).

In a study undertaken by the National Autistic Society (NAS), 17% of children had been excluded from school at least once, with half of these having been excluded on at least three occasions (Reid, 2011, p. 8). In addition to formal exclusions, 32% of the parents responding to the NAS survey had been asked to pick up their child early or take them home at lunchtime, 19% of parents having been asked to do this on more than four occasions (Reid, 2011, p. 8). Such requests tend not to be recorded as exclusions, but government guidance indicates that such informal exclusions are illegal, whether or not parents or carers agree, and should be recorded (Lamb Inquiry, 2009, p. 34; Reid, 2011).

Parsons et al. found:

> Parents of children with ASD were significantly more likely to report formal exclusions from school…[and this]…suggests that urgent action is needed to understand the context and implications of formal exclusions for young people with ASD (2009, p. 55).

In this study, four children had experienced a fixed term or permanent school exclusion and one child was moved to another school in order to avoid exclusion. Parents also spoke of so-called 'informal exclusions', such as described above, where children were withdrawn from school by mutual agreement. The experience of exclusion is individual for each family. I have chosen to focus on David's story as related by Linda as it is the most complex of the accounts of an exclusion experience told by a parent in this study, both because of the various issues it raises and because of the length of time David was out of school.

David was diagnosed with an ASC when he was five and received a statement of SEN while in infant school. As discussed in Chapter Seven, Linda experienced a difficult confrontation with David's junior school headteacher, but she was relieved when David was offered a place at a secondary school with a good reputation for meeting the needs of children with ASC/ASD. The transition to secondary school was well planned and organised and Linda found the SENCo helpful and willing to make special arrangements to help David cope with the move. Despite efforts to enable David to settle in his new school, he showed signs of stress, including absenting himself from the building without permission and talking of killing himself. Linda spoke of David "attacking" her and "trashing" the house on many occasions after a stressful school day.

Towards the end of the Spring Term of David's first year at secondary school, there was an altercation involving David and another boy at the end of the school day:

> I'd gone to pick him up from school and one of the other boys came across in front of David and said something to David and David went for him. I dashed up to get them apart and David bit me. He bit my thumb. I managed to get him off but…Somebody came out [of school] and said, "Come on, come back in." I took him back in…

When David had calmed down, they went home, but:

> When I got home, I got a phone call from the Deputy Head to say that they were going to exclude David for two days.

This was the first time David had been excluded from school but Linda was not unduly concerned, recognising he might benefit from a break from school. Three days later, on Saturday morning, Linda received a further phone call from the Deputy Head, asking to meet that day. The Deputy Head explained the school management team had discussed the situation and, in their opinion, it was clear David was not coping and that the school could not look after him properly. David was permanently excluded from school:

> It was obviously a bombshell. I mean, I could see why it had happened in a way, but in another way it was like, "Well, is that it – no more – what's going to happen now?"

Linda was told David was entitled to out of school education provision, but was not told how this would be arranged, so contacted the local authority herself:

> She said, "Yes, we've got to sort out a tutor and various bits and pieces but it will all be done." And we waited, and we waited, and we had another meeting at the school…This was March. We had a meeting just after he got excluded and then we had another meeting the following month…I was getting really fed up with the lessons not happening…I phoned the school and they said, "It's the Education Welfare Officer's responsibility." And I phoned the Education Welfare Officer and she'd say it was the school's responsibility…In the end I got so cross and I went down to school and asked to see the Deputy Head and was told, "Oh he's busy at the moment." I mean this is after a few months. "He's busy at the moment."…I sat down and I waited and he came out to see me…He said, "Right, we'll sort this out. I'll phone somebody…We'll have a meeting next week."…Well we didn't get a meeting the next week, but we got one the following week.

It took six months from the date of the exclusion before David's out of school education was put in place. In David's case, the arrangement was complicated as it was agreed he required one-to-one tutoring rather than a place in a Pupil Referral Unit, but this does not account for the delay in agreeing the provision. Children who are excluded from school continue to have a legal entitlement to education, and public resources are available to address what is recognised as a 'public issue'. However once David was no longer on a school roll, the only person ensuring David's needs were addressed was his mother. Linda's previous experience

prepared her to be proactive and to inform herself of David's rights. She was not prepared for David not to receive his entitlement to education. It is unclear why obtaining a signature on the paperwork took so long, when either the school or the education welfare officer could have acted. The personal cost for Linda was also considerable:

> That was such a difficult time – and, it's funny how you, when you kind of live through those times. you just get on with it. It's not until you think about it afterwards, and you just think, "How did I keep going?" Because I had David at home all day, and then I went to work all evening, and then I got up in the morning, and had David at home all day and then I went to work in the evening. That was what my life was like. And I don't know how I kept going for so long really.

Arranging out of school education was important, but an even greater priority was finding a permanent school placement for David. Local authorities are obliged to ensure efficient use of public resources and therefore look for the most economic option that can address a child's needs adequately. Another parent, Lynn, spoke of how in a meeting with the education officer responsible for negotiating a placement for her son, she was told the local authority would not provide a Rolls Royce if a mini would meet her son's needs.

The initial suggestion that David should be placed in a local authority special needs school was viewed as inappropriate by David's parents as his educational choices would be restricted and he would be unable to take a full range of GCSE subjects. However, they agreed to David receiving his out of school education support on the special school premises, confident this would demonstrate the inappropriateness of the setting. After three weeks, the tutor appointed to teach David spoke to Linda:

> It was a very noisy place. So even in a separate room, he couldn't work properly because there was all this noise going on. [The tutor] said to me, "This isn't going to work because you know, it's too noisy. They keep giving us different rooms." One day they gave them a room that the staff lockers were in and the staff kept coming in and out of the room while they were working. [The tutor] said, "This is absolutely stupid…He can't even think in there because of the noise that's going on, let alone all the interruptions and whatever else…It's not working."

The local authority agreed not to pursue this school option. By cooperating with the education officers, David's parents demonstrated the proposed provision was inadequate, exercising their agency through passive resistance. Linda said that they were prepared to "fight" the local authority if a placement at this school had been imposed on David.

David's parents were proactive in exploring school options, consulting advice agencies, searching the Internet and speaking to parents who had confronted similar issues. By so doing, they increased their knowledge of the special needs domain and of what provision might and might not be possible to support David. Anticipating difficulties, they engaged a solicitor, but, once they realised the potential costs of legal advice, they found alternative

sources of advice. As the local authority had not suggested any other schools that they considered appropriate, David's parents identified and visited a number of specialist schools, recognising some would be unable to meet David's needs. During this period, they paid for a residential assessment at a school for children with AS/HFA, but this school concluded David required more specialist intervention than it was able to offer. Eventually, the local authority suggested possible schools, each of which had to be visited.

This was a trying time for David's parents. Linda was finding it difficult to cope and was offered counselling by her family doctor, but this proved an additional source of stress:

> It was on a Tuesday morning…I would come away from there feeling quite depressed because I'd sat there and talked about it the whole time and at the end of my 6 sessions or whatever it was I actually felt that I had wasted an hour and a half of very precious time that I could have had to myself…David was having 5 hours a week tuition, and I would take him for his lesson, go for my appointment and leave the appointment and go and pick him up from his lesson…I'd wasted an hour and three quarters that I could have had to myself…Because David was having 5 hours a week, that was my 5 hours a week to do things that I needed to do…Like if I needed to go into town, I would do it while he was having his lesson, because it was easier for me to do it than to take him into town…I would spend my 5 hours a week doing things that were necessary for the running of the family that I couldn't do with [David] around.

It was not possible to leave David unattended at home, which meant Linda became his full-time carer during the daytime, his father taking over responsibility in an evening when Linda was working. Counselling became an additional demand on Linda's time, rather than a support, suggesting service providers need to consider the potential implications and unintended consequences that might be associated with some support services.

When David had been out of school for about twelve months, the local authority arranged an assessment by an independent specialist school, local to David's home address. David's parents had visited the school and decided it could not meet David's needs but again complied with the local authority:

> I knew they were going to say, "No," but you have to go through the agonies of it all.

The visit took place before a school half-term holiday and the headteacher said he would inform the family of his decision before the holiday started:

> They didn't phone…Then on the Monday [the education officer] phoned…He said, "OK, I'll ring them." So, he rang the Head at [the school] and asked him if they were going to offer David a place, and the Head said, "No, he needs to be in a specialist autistic school." And I thought, "Thank you that man." [The education officer] phoned back, and said, "You find the school, we'll find the funding. The headteacher suggested [school name]." So that was the biggest relief ever.

David's parents visited the recommended school and David was offered a place, which he took up at the beginning of the following school year, eighteen months after being permanently excluded from mainstream secondary school.

Linda, like other parents in this study with sons in residential placements, was aware of David's needs escalating the longer he was out of school, resulting in the need for more specialist resources than might have been necessary if the response was more timely, when the problem first became evident. Although Linda and her husband were compliant in meeting all the local authority demands, they viewed this as a battle strategy, in which they visited schools in order that the schools themselves would declare themselves inappropriate to meet David's needs. It was only when the local authority excluded all the options it had available that the education officer was able to exercise the agency to tell Linda to find a school and the authority would pay. In reality, this was a commitment he could not make as the final decision about a school placement was not his, but belonged to a placement panel. Throughout the process Linda not only exercised agency in complying with the local authority, but also in ensuring she was fully informed as to what the options were for David. Linda logged 158 telephone calls to local authority officers and kept copies of correspondence and notes of all discussions with schools and practitioners, describing negotiating David's school placement as a full time job.

Discussion

The permanent exclusion of a child with special needs presents several layers of complexity. There is a requirement on the local authority to make both short term and long term arrangements for a child's education and to do so in a manner that makes efficient use of public funds. Children with statements of SEN have a designated 'caseworker' in the local authority. In practice, this person is an administrative officer and not a key worker as might be inferred from the job title. Once a child is out of school, it is possible for them to become hidden, unless a parent is proactive in working on behalf of their child. In this account, without Linda's intervention, it is possible David's out of school education support would have been further delayed. Placement decisions are made by a panel, comprising local authority officers and others with specialist educational knowledge, but the panel membership may not include anybody with direct knowledge of a specific child. The emphasis on inclusion in mainstream schooling, as outlined in Chapter Three, means that whenever possible placement is made in a mainstream setting, or other local school. Similarly, some practitioners, who have been trained in settings advocating inclusive practices, regard specialist placements as segregationist, and to be avoided. A concern for parents, when a school placement has failed, is avoiding placement in another school where there is a risk of failure, leading to further interruptions to the child's education. Although all parties may want what is best for the child, views on what is best for the child may differ.

As can be seen in this account, the practitioner who knew the child best, the tutor, had minimal influence in determining how David's needs should be addressed, being limited to arranging an alternative venue for out of school education. The practitioner who appeared to have most influence, namely the education officer was also limited by the requirement to consider all available lower cost options before considering more expensive solutions. Although this may appear an efficient use of public money, it can be argued that this is only an efficient use of resources in a short term context and only when viewed from a financial perspective. When future needs are taken into account, the potential cost to the public purse may escalate if children and young people do not receive an appropriate and adequate education. A third of eighteen year olds with SEN are so-called NEETs, meaning they are not in employment, education or training, (Public Accounts Committee, 2012). Although the percentage of people with SEN in the prison population is not known (Talbot & Riley, 2007), Anderson and Cairns (2011) suggest that 30% of male prisoners are dyslexic, and NEETs are considered to be at greater risk than other young people of being drawn into criminal activities. The restriction of expenditure on meeting the needs of children with special needs may have longer-term social and economic consequences for both individuals and society as a whole. These consequences may remain hidden as the budgets for addressing special education are locally controlled and separate from the budgets for criminal justice and employment training.

Curiously, the person who had most influence in this account was the headteacher, who acknowledged his school was not able to meet David's need. By saying 'no', he enabled the education officer to work together with the parents to find and finance an appropriate placement.

I have already acknowledged the proactive role undertaken by David's mother in ensuring his needs were addressed, but it is also appropriate to consider the personal cost to Linda and her husband during the eighteen months David was out of school. During that time, not only was there a toll on Linda's health, as evidenced by the counselling she received, but the family incurred the expense of specialist legal support, travel costs visiting different schools, the fee for a residential assessment and various administrative costs. The reward for Linda has been to see David settled in a school where he is now thriving.

Children's services and safeguarding (child protection)

Local authority children's services provide support to children with disabilities and their families, but many children with special needs who are considered as disabled by other public bodies do not qualify for assessment or support from these services (Goodley & Runswick-Cole, 2011). I have been unable to find published research relating to the use made of social work support by parents of children with AS/HFA, but I am aware from general reading and

conversations, both online and in person, that some parents of children with AS/HFA are reluctant to approach children's services for support, especially when their concerns centre on sibling relationships, and in particular the behaviour of their child with AS/HFA. John, a consultant paediatrician, spoke both about children with AS/HFA not meeting the criteria for referral to the child disability team and of the emphasis placed in children's services on child protection, which means some families do not meet the criteria for general social work support unless they become families with a child protection issue:

> We have for a number of years a very, very poor social service input…Now it's vested on the child protection bit…On a national basis, a lot of children we work with would qualify as a child in need. Locally, unless you reach criteria for the child disability team, which basically means you've got to have a severe learning difficulty plus other problems, you won't meet their criteria. And the mainstream bit of social services…will not give any input until the point where the parents do something that gets them into child protection, and then they can become a child in need. And I have had a number of families where we've highlighted that they're on the edge and if [they] don't put the input in something's going to happen, which will get them into child protection. And it's happened. And we say, "We told you so. Why didn't you intervene when we asked you."

Two of the families in this study are known to have had contact with either social services or children's services.[14] In one of those families, the mother was a former social worker, who made a self-referral to children's services, requesting an assessment of her child's needs and a carer assessment for herself.

The other family was referred to 'child protection' following an incident in their home, when a support worker from another agency was present. Janet was familiar with ASC through her work and had spent considerable time investigating possible interventions that might assist her son, Charlie. The incident that caused concern, and led to a referral to children's services, also involved her daughter, Amy. At the time of the incident, Janet was actively seeking additional support for her son. She had been advised by her son's paediatrician to seek support from the local Family Mental Health Services. Even though it was acknowledged this might not provide the support Charlie required, it was felt to be a necessary step before a referral could be requested for an 'out of county' assessment. The excerpts quoted here are from email correspondence and pseudonyms are used:

> The family support person came round today…and suggested we play a game with questions…One question was "I get really cross when?"…That set Charlie off. As soon as he started talking about his experience, he began to relive it, and he attacked Amy, hitting her over the head, etc. I got him up to his room…Amy was of course hurt and upset, and the support worker was visibly shocked. She said she felt she needed to

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[14] As discussed in Chapter Three, social service departments were split into adult and children's services in 2004, but there is a tendency for people to continue to refer to social services rather than children's services.

report this to Child Protection, as Amy is in danger and at risk of being hurt.

By complying with advice to seek support from a service that was unlikely to provide appropriate support, Janet felt that she had created a situation that caused her daughter anxiety, had taken the focus away from Charlie's needs, and could damage the integrity of the family unit. Elsewhere in the conversation the support worker had attempted to reassure Janet, saying that [children's services] were not in the business of splitting up families, but that maybe [a referral] would help us access the services we needed. The use of the phrase "splitting up families" did nothing to remove Janet's anxiety, but instead exacerbated her concerns. Janet's email to me ended, "Why is it such a struggle to get help?"

Janet did not deny the volatility of the family situation, but she was in a situation she had not been in before, had not expected to experience and was not prepared for. Like other participants in this study, she found herself in a place of disjunction, experiencing a hysteresis effect, which required a readjustment of her predisposition to cooperate with practitioners, to a state where she was equipped to defend her family and to make a clear statement of the support she was seeking for Charlie and for the family. In further correspondence with practitioners, Janet acknowledged that both Amy and herself were at risk of injury, but consistently requested that Charlie be formally assessed by specialists with expert knowledge of his condition. She also set about acquiring additional knowledge so as to ensure she was fully informed as to what she should and could expect from children's services, and what she might expect from a social work visit. This preparation increased Janet's cultural capital and was part of the reshaping of her habitus to equip her to deal with an unfamiliar *field* of struggle.

A month later, following a number of telephone conversations, the family was visited by a social worker. During the course of the visit, the social worker agreed, "The referral to the Children's Safeguarding team should not have happened," and also made it clear children's services would be unable to offer support. Janet wrote:

> It was quite clear through our conversations that social services can't provide anything that I want and he didn't suggest that there would be any assessments forthcoming. He said that the disabilities team only started dealing specifically with autism two years ago…They focus on children much further down the spectrum. It is clearly a question of resources.

Although this meeting was inconclusive in terms of progressing additional support for her son, Janet felt she had been heard and understood by the social worker, in contrast to meetings with other practitioners where she felt she was viewed "as a difficult person who won't engage in the way that they want."

However three days after the meeting, Janet received a draft report from the social worker, which caused further concern:

> Kind of him to send it to me for comment/correction. I feel so angry about the information obtained from the school. It is all incorrect...The statement that [Charlie] does not have behavioural difficulties in school is nonsense. And finally, what just makes my blood boil, is the idea that it's [Charlie's difficulties] about boundaries and we are somehow too soft. I just want to scream…I am becoming increasingly wary of having information on file that can be used in the wrong ways. I do intend to write back to him, and I certainly am going to express my disappointment at the school's lack of understanding. Argh! Sometimes it just makes me wish I hadn't bothered trying to pursue help.

Janet's frustration is palpable. From her perspective, she has kept to the rules of the game, to use Bourdieu's expression, but the outcome has been one where inaccurate information is being promulgated about herself and her family, leaving her wary of seeking assistance and of placing herself in a position where information about her and her family is on file and can be used in unhelpful and negative ways. Perhaps most worrying is Janet's final comment about wishing she had not engaged with the public authorities in seeking to access support for Charlie. Rather than reducing the 'personal trouble' experienced by the family, it had become subject to scrutiny in the public domain, and the burden on Janet and her family had increased. Rather than receiving expert support and assistance, Janet found she was working with practitioners with less knowledge of AS/HFA than she had acquired, but who acted as though they had expert knowledge in their interactions with other practitioners, while acknowledging Janet's expertise in less public exchanges.

Inadequate or inappropriate public response – practitioners' agency

Even when it is clear a particular resource might be helpful, it is not necessarily available. Lynn recounted an incident that occurred when Sam, a young man with AS/HFA, dyslexia and ADHD, was twelve years old and the family was receiving support from both CAMHS and social services. A referral had been made for the provision of respite care, but this had not been provided as the resource was not available. One reason for the lack of the resource might be the insistence of the local authority that respite care should be provided in a family context, limiting the supply of respite care to the number and appropriateness of people available to offer this service.

Sam's behaviour was very problematic at both home and school, leading to a number of assessments, and referral to the Tier 3/4 CAMHS regional resource, a hospital based mental health team with peripatetic staff. Members of the team visited the family regularly in order to support Sam and advise his parents on behaviour management strategies. Apart from Sam

becoming increasingly withdrawn and aggressive, both the CAMHS team and Sam's parents were concerned about Sam's growing addiction to online, interactive, computer gaming, which was causing him to become semi-nocturnal in order to facilitate communication with gamers in other time zones and to participate in 'guild' activities. Gaming was taking priority over real life activities. The CAMHS team advised Lynn to restrict Sam's Internet access, resulting in a series of meltdowns. One particularly serious incident occurred on a Friday afternoon, when Sam "trashed" his bedroom, destroying his furniture and punching holes in the walls and door, and using threatening words to his parents. Lynn contacted the CAMHS team for advice, and an immediate home visit was arranged. Sam refused to speak to anybody

> [One of the CAMHS team] rang the social services emergency number, but it was Friday afternoon, so nobody could do anything. We were desperate for some kind of respite. We had been asking for it for months. But they said they had nowhere secure enough, and they said our only option was to call the police.

Somewhat reluctantly, Lynn agreed to the police being contacted; she thought one of the CAMHS team made the phone call. Sam was arrested, charged with causing criminal damage and taken away by the police. Lynn was extremely angry and distressed by this turn of events and that the CAMHS team had failed to address Sam's needs in a more appropriate manner. She believed police intervention would not have been necessary if the warning signs of an impending crisis had been heeded. Lynn also considered Sam's problems were compounded, as he had received a police reprimand and therefore had a police record. Lynn felt powerless to act, other than writing to her Member of Parliament alerting him to the problem

> We are the parents of a 12-year-old boy diagnosed with Asperger's Syndrome, Attention Deficit Hyperactivity Disorder and Dyslexia. My son has recently received a statement of SEN, following statutory assessment by [XXX] LEA, and we are currently negotiating a school placement for him. He is also a patient at [YYY] children's psychiatric unit and we have had an assessment of needs by the local authority caring services.
>
> For some months I have been pointing up to the various authorities the deterioration in my son as he has entered puberty. He has become more withdrawn and verbally and physically aggressive. Up until now no appropriate respite care has been available.
>
> Last week, we were faced with a situation where my son on two successive days did a considerable amount of damage at home including effectively destroying his bedroom and punching holes in the internal walls of our house. The only advice available was to contact the police. We were then faced with the only action they could take being to arrest my son for criminal damage. Staff from [YYY] were present as was a friend with professional expertise in autistic spectrum disorders and Social Services were contacted. There was general agreement that what was really needed was a safe place where my son could be cared for, perhaps

overnight, and which would give us space to clean up the mess and prepare ourselves for the next onslaught. No such place of safety was available and we decided we had no option but to allow our son to be arrested. Due to his disabilities, the arrest and associated procedures had little or no meaning for him, and in no way could he be said to have been given the kind of lesson or warning that such an experience might be for a child without his difficulties.

I understand from email lists of parents of children with similar problems to my son that this is by no means an isolated incident, and it would appear that there is little or no emergency provision anywhere in the country for children such as my son. Yet it is by no means uncommon for children with these disorders to be extremely disruptive.

I would be grateful if you would enquire of the appropriate authorities what provision can be made for children in this situation. How many disabled children and young people are subjected inappropriately to police intervention in the face of the absence of appropriate place of safety provisions?

Lynn is an articulate woman who had researched the resources that should be available to support Sam and her letter clearly identifies the problem, as she perceived it, and the inappropriateness of the action taken by the various practitioners involved, actions the practitioners had little control over due to lack of resources, resulting in them having little agency.

Sam's difficulties were recognised as part of a 'public issue' that can be categorised as child and adolescent mental health. The public response was an assessment by social services and CAMHS and ongoing support in the home. Sam's parents shared their concerns with the practitioners and requested respite care as a way of de-escalating the tension in the home. When an emergency arose, the practitioners involved with the family did not have the capital/resources to provide appropriately for Sam, resulting in a lack of agency. The requirement for respite care was agreed before the emergency arose, referrals were made, but the practitioners were unable to make the provision. When the emergency arose, the identified resource requirement was a secure place of safety, but the CAMHS team were unable to provide this. The options were to do nothing, or to involve the only public body with agency to act, namely the police. What both the family and the practitioners considered more appropriate provision was not available. The police were empowered to remove Sam from his home, but they were not able to offer a secure place of safety and were limited to arresting and criminalising a boy with complex mental health problems and special needs. Arguably, Sam's parents could have exercised their agency by refusing police involvement, but they were not advised this was an option and if they had made this choice, the problem remained of how to deal with a crisis, which for them was a 'personal trouble' requiring public intervention. In writing to their MP, they were aware he had no agency to assist with their problem, but they recognised that what they had experienced was not an isolated problem, but one experienced by other parents of children with AS/HFA.

Twelve months later the local authority placed Sam in a specialist residential school. Eight years later, he is an undergraduate. Under current guidelines (ACPO, 2006) the record of this incident will remain on the police national computer until Sam reaches the age of one hundred. Although, a reprimand does not give an individual a criminal record, it does have to be declared when applying for an enhanced Criminal Records Bureau check, so could impinge on Sam's future occupational choices.

This incident happened in 2004. The detention of young people with mental health problems is a continuing issue. On 18th November, 2012, the BBC reported that during 2011, 347 children and young people with suspected mental health problems had been detained in police cells, in the absence of an appropriate place of safety (Beckford, 2012). This is a 'public issue', being addressed by a public response, but a public response that is recognised as inappropriate, and that leads to an ongoing 'personal trouble' for the affected individuals.

Concluding reflections

The accounts in this chapter, like the accounts in the preceding chapters, illustrate a range of difficulties encountered by parents in ensuring their children's needs are addressed. These include difficulties in accessing information, communication problems, failures of partnership between school and parents, difficulties with referrals, recourse to the private sector, and cost to the family in getting their child's needs addressed. Perhaps most worrying in these accounts are administrative failures, where papers were lost or unsigned, leading to delays in addressing children's needs; delays in making appropriate provision while different departments decide who is responsible for what; and the potential long term effect for a young person who acquires a criminal record for behaviour due to a known autistic spectrum disorder. It would appear some of these failures would be mitigated by the appointment of key workers with an appropriate level of seniority to make recommendations, if not actually to make decisions.

Joan, an educational psychologist, referred to:

> Times when you think the current system's being abused to be honest by people who've got the money to do it, because it's not the vulnerable people who go to Tribunal.

Reflecting the ideas that those children with special needs who receive the best support and most resources are not necessarily the most needy, but are children of middle-class parents who are prepared to pay and to shout the loudest to get their needs met. There is evidence that middle-class parents do use their social and cultural capital to leverage support for their children (Matthews & Hastings, 2012; Vincent, 2001; Vincent & Martin, 2000, 2002) in interacting more with practitioners, but does that mean either that other children do not

receive support they are entitled to, or that other parents do not also 'fight' on behalf of their children?

This study suggests that although those parents who are most affluent in terms of all types of capital are prepared to engage in action that results in their voices being heard, the impetus driving all the parents was ensuring their children's needs were met. There was evidence of 'less affluent' parents seeking information and advice, sharing their knowledge with others and supporting them in accessing resources and ensuring they had prepared themselves to engage in 'fighting' on behalf of their children, should this prove necessary. More affluent parents might be prepared to engage more quickly with practitioners, but other parents were equally prepared to engage when they were concerned their children's needs were not being addressed.

Linda had little knowledge of special needs, AS/HFA or the education system before David was diagnosed, and she had no expectation of having to struggle to ensure his needs were addressed. However, having found herself in a situation where she felt unable to fight adequately for what she believed her child was entitled to, she equipped herself in preparation for any future battles. Linda describes herself as an intelligent woman, but nothing in her background or prior experience prepared her for the struggle she engaged in on behalf of David following his permanent exclusion from school. She was of the opinion that the local authority mainstream and SEN provision was not going to meet the needs of her intellectually able son who was prevented from accessing the curriculum because of his ASC/ASD, and proceeded to ensure his needs were appropriately addressed, not through open 'warfare', but through cooperation and determination to demonstrate which resources would and which would not meet David's needs. A parallel can be drawn with Paula's experience of getting an assessment and diagnosis for Aran; she did not engage in a 'fight' with the clinic, but instead accepted every appointment, stating Aran's needs until eventually she was heard and Aran was assessed and his needs addressed.

Whereas more affluent and articulate parents, who share the habitus of the practitioners they interact with, may use their resources to engage in a visible 'fight', this evidence suggests that other parents also 'fight' but do so using different tactics and resources.

Although the special needs domain is adversarial, as described in public documents, it appears that those incidents where 'fight' is evident are the visible and most evident aspects of a troubled domain. Far more difficulties experienced by both parents and practitioners are largely hidden from public view, reflecting 'personal troubles' and struggles experienced in the personal domain space of home and work. Even when difficulties become visible, struggle turns to fight, and the problem attracts a public response, the individuals concerned continue to experience the problem as a 'personal trouble' and struggle.

There is evidence that some of the factors influencing the development of the special needs domain, as discussed in Chapter Three, underpin some of the experiences of 'struggle' and 'fight' experienced by parents and practitioners. The emphasis on inclusive education and avoiding segregation can mean a specialist school, and, in particular, a residential school might be regarded as a last resort, not only on the grounds of cost, but also in order to avoid segregation, even when it is the view of some practitioners and/or the parents that such a placement is in the best interests of the child. The emphasis on inclusion and removing disabling barriers can mean some practitioners view as failure, a child being educated elsewhere than in a mainstream setting.

Similarly, the emphasis on collaboration and partnership working, while welcomed by some practitioners, challenges others. Though practitioners work together they may express doubts about the expertise of others, especially when some practitioners claim greater knowledge of a child and their needs than other practitioners, as was seen in the views expressed by John, the community paediatrician, and Kerry, the special school teacher, in Chapter Six.

Possibly surprisingly, there are similarities in the experience of practitioners and parents of working with or parenting children with AS/HFA. Although they are sometimes found battling each other, they share a common value system of seeking to address the needs of the child. Practitioners take decisions about how to recognise and address difference in their practice, while parents cope with living everyday with difference. What appears to be missing is an absence of understanding amongst practitioners of what it means to parent a child who is different, every day and in an alien world. Similarly, parents do not, and perhaps cannot, understand the tensions and frustrations of practitioners when confronting their everyday 'personal troubles', and balancing the requirements of sometimes conflicting agendas. Although changes in legislation and increasing public awareness may assist in reducing the level of adversarial responses in the special needs domain, it would appear the domain will continue to be a site of fight and struggle.

Chapter Nine – Conclusions

This thesis has explored the 'struggle/fight' metaphor as experienced by those working with or parenting children with AS/HFA. It is rooted in my personal experience, as the mother of a young man with AS/HFA. Although the SEN Code of Practice (DFES, 2001) emphasises *both* collaboration between agencies *and* partnership with parents, I used militaristic language when speaking of the experience of ensuring my son's needs were appropriately addressed and, as facilitator of a parent support group, I heard other parents using similar language when discussing their relationships with practitioners. I did not understand why the special needs domain was adversarial. Government reports have tended to focus on reviewing and restructuring the SEN system and much published research has explored tensions in the relationships between parents and practitioners, parents' coping mechanisms, and organisational arrangements. My sense was that such approaches represented a reductionist approach to problem solving and that there was a need for a more holistic exploration of the tensions experienced in the special needs domain. *Systems* approaches provide tools for exploring complex problems from various perspectives with the aim of identifying the range of factors underlying a problem situation and the actions that could be taken to ameliorate the situation, recognising the consequences, intended and unintended, that might stem from different actions.

Whilst it is clearly beyond the scope of a doctoral thesis to attempt to solve the problem of the adversarial nature of the special needs domain, I considered a whole *system* approach would facilitate a more nuanced understanding of struggle and tension within the domain. The advantage of using a *systems* framework in researching a complex problem is not only that it is holistic, but it is eclectic, drawing on a range of tools, techniques and theoretical perspectives. In this investigation, I explored the influences shaping the special needs domain, used diagramming techniques to map the domain and processes within the domain and drew on theoretical insights from Bourdieu, Bronfenbrenner and Mills in order to understand the experience, context and dynamic of tension within the domain.

During the time this research took place, the SEN system was subject to review by the UK government. I do not directly address the review in my thesis, but nevertheless it formed a backdrop to my study, especially as one of its aims was to address and minimise the "adversarial nature" of the SEN system (DfE, 2011, p. 8). Even if there had not been an ongoing government review, it would have been impossible to ignore the reality that there had been calls for reform to the SEN system for many years. Expectations that New Labour would reform the SEN system were overtaken by the Laming inquiry (Laming, 2003) and the adoption of the Every Child Matters agenda, which both recognised any child might have 'additional needs' and placed an increased emphasis on child protection and safeguarding,

arguably resulting in a diminution of attention on the needs of disabled children and children identified as having SEN (Goodley et al., 2011). During the latter years of the New Labour administration a number of reports were published focusing on problematic aspects of special needs policy, provision and practice (Bercow Report, 2008; House of Commons Education and Skills Committee, 2006; Lamb Inquiry, 2009; Salt, 2010). Problems within the SEN system were highlighted during the 2010 General Election campaign in a high profile encounter between David Cameron, leader of the Conservative Party, and Jonathan Bartley, the father of a child with spina bifida, when Bartley challenged aspects of the Conservative manifesto in relation to disabled children and Cameron acknowledged the fight parents engage in when seeking support for their children (Brown, 2010).

Later in this Chapter, I discuss the implications of my research findings for different audiences, including policy makers, practitioners and parents, but firstly I turn to my theoretical and analytic framework and locate a whole *system* approach within its wider theoretical context. I also consider how the work undertaken in this study could be extended, returning to the positioning of the child and young person with special needs and considering how children and young people might be more fully included in research in the special needs domain.

Theoretical and analytic framework

The study discussed in this thesis utilises a whole *system* framework derived from the *systems* transdiscipline (Jackson, 2000). Rather than developing a deep understanding of a narrow subject area, a whole *system* approach, as its name implies, uses both wide-angle and telephoto lenses to understand the breadth, depth and interconnectivity of problem areas within a broad domain. Although *systems* approaches have been adopted in many disciplines, they appear to be less well-known in sociology, sociologists tending to associate 'systems' with the 'social systems' theories of Parsons (1951, 1961) and Luhmann (King & Thornhill, 2005), rather than the *systems* transdiscipline. This does not mean *systems* thinking ideas are absent in sociology; as discussed in Chapter Two of this thesis, they are present in the writings of Bourdieu and Mills and, though not explored in this study, in the laminated models and interdisciplinary approaches evident in critical realism (Bhaskar, 2012; Elder-Vass, 2007; Mingers, 2011).

Whereas the phrase 'whole system' may be assumed to imply that the whole *system* is the focus of an inquiry, this need not be the case. With most domains an extensive body of knowledge already exists pertaining to different aspects of the domain and its subsystems. The whole *system* provides a context for the study, permitting the researcher to identify specific aspects of the domain for more detailed examination while recognising these are aspects of an interconnected whole. Allegorically, a whole *system* may be viewed as a

multidimensional jigsaw, where existing knowledge interconnects with new insights, contributing to a fuller understanding of the whole. Using a whole *system* approach can be challenging, as I found when attempting to weave together the 'big picture' of the systemic roots of tension with the lived experience of parents and practitioners. However viewing the tensions and struggles discussed by participants within the context of the whole domain revealed these often had little to do with the formal structure of the domain and, by implication, were unlikely to be ameliorated by changes such as those envisaged in the SEN review. This approach also facilitated the recognition how influences on the whole *system* impacted on the experiences of those working with and/or parenting children with AS/HFA, as can be seen, for example, in the discussion of assessment and diagnostic processes and in practitioners' reflections on collaboration. Using a whole *system* approach revealed that not only did all participants experience tension and struggle, but there were similarities between the challenges faced by parents and those faced by practitioners.

Scoping the study and establishing the domain boundary

Systems approaches offer a number of different techniques for visualising, diagramming and modelling *systems*. In this study use was made of spray diagrams and *systems* mapping. An initial spray diagram provided a tool for discussion, identifying the main elements of the domain and determining a *systems* boundary. This led to diagrammatic representation of the whole *system*, which can be found in Chapter Three (Figure 2). *System* maps were then developed relating to subsystems of the domain and processes within the domain. These diagrams did not all find a place in the final version of my thesis, but the creation of the models facilitated my understanding of the domain and permitted an exploration of how different parts of the domain are interconnected. They also facilitated decisions about where to draw the domain boundary, which elements to include within the boundary, and what could be considered influences or constraints on the domain. The diagrams were refined initially through discussion with others knowledgeable about the domain, but as the *system* maps were developed, they were placed on a wiki and comments were invited from a number of specialists in the field. As a result of comments, the *system* maps were refined: a process representing a form of coproduction. Links to the wiki and the set of *system* maps are to be found in Appendix A.

Diagrams are not only useful as part of a research process, but have practical applications. In the context of this study, they can be used by policy makers, practitioners and parents to facilitate understanding of the domain structure. They can also be developed to facilitate understanding of how and where different practitioners are located, and how the different subsystems comprising the domain link to each other. A further application is identifying the different elements involved in specific processes, such as assessment or diagnosis. The diagrams created in this study could be updated to reflect changes in special needs provision

once the Children and Families Bill (HM Government, 2013) is enacted. Such diagrams might be used to provide information about the domain to parents, practitioners and others, perhaps being used in training materials.

Theoretical eclecticism

As a transdiscipline, *systems* thinking has its roots in many different traditions and theoretical perspectives. This gives the researcher the freedom and flexibility to adopt an interdisciplinary approach and draw on ideas that would not necessarily normally be associated with each other. These ideas can be used to develop theoretical frameworks for interpreting the data and presenting research findings. An example of this can be seen in Chapter Seven where I use the Bourdieusian concepts of cultural and social capital together with Bronfenbrenner's ecological *systems* model to draw the mesosystems of different parents and practitioners. Other researchers have used Bourdieusian concepts of capital to investigate relationships between parents and practitioners in educational settings, revealing links between different forms of capital, social class and parental involvement with children's education (Gazeley, 2012; Nind, 2008; Reay, 2000; Vincent, 2001; Vincent & Martin, 2000, 2002). As described in Chapter Seven, combining Bourdieusian concepts with Bronfenbrenner's models provided a way of differentiating not only the positioning of parents, but also of practitioners, and led to an exploration of the effect of the possession of different forms of capital on relationships between parents and practitioners. This led to the unanticipated finding that whereas less well-endowed parents relied on practitioners' knowledge and expertise, better endowed parents were less reliant on practitioners for information and could be viewed as opponents by less knowledgeable practitioners, resulting in conflict between parents and practitioners in ways that obscured the needs of the child.

Throughout the chapters discussing my research findings, I have used Mills' (1959) differentiation of personal troubles and public issues to develop a framework for understanding the various forms of struggle experienced and engaged in by parents and practitioners. While this binary distinction is useful, I found considerable blurring between the personal and the public, especially when experiences were contextualised in terms of location and consequences. If a problem is contained within a private space, it may be regarded as either a difficulty or a source of tension, but in a public space, the same problem may cause additional stress, leading to it being viewed as struggle. If the public authorities become involved, the problem continues to be experienced as personal, but the statutory response may lead to conflict and the use of militaristic metaphors. The differentiation of personal and public offered a useful framework for understanding some of the layers of complexity present in the struggles narrated by participants in the study, especially when complemented by the theoretical insights offered by Bourdieu.

Extending the use of systems approaches

Systems approaches have been used in this study to provide a research framework, to create visual representations of the domain and to enable different theoretical perspectives to be brought together. It is curious that there has been little adoption of *systems* approaches in sociology compared with some other disciplines. Mills observed in 1959 that social structures were increasing in their complexity and this has continued to be the case during the past half century. As *systems* approaches are designed for the study of complexity and complex problems, there is a case to be made for using more *systems* methods and techniques. Among other tools, I consider feedback loops (Senge, 1990), rich pictures (Checkland, 1999) and force field analysis (Ajimal, 1985; Burnes & Cooke, 2012; Lewin, 1951) to be worthy of exploration and experimentation. For example, rich pictures could be used in research studies where participants' perceptions of a *system* are relevant. This technique was developed in soft systems methodology (Checkland & Poulter, 2010) and offers a structure for creating a visual representation of how people perceive the *systems* they are part of, including areas of conflict, positive and negative influences, barriers and other aspects of a *system*. Such diagrams can be developed individually or within a group setting and provide rich visual data as well as a basis for discussion and further exploration.

At a time when the importance of interdisciplinarity is acknowledged, a whole *system* approach offers a framework for interdisciplinary research design and for exploring complementary theoretical perspectives.

Addressing the research questions

The primary research question identified in Chapter One of this thesis asked why the special needs domain is experienced and described as adversarial when it is founded on a basis of partnership and collaboration. In exploring this question, I considered first the structure and functionality of the systems comprising the special needs domain and how these contributed to tensions within the domain. Secondly, I focused on the experience of those working with and/or parenting children and young people with AS/HFA. My findings are summarised in this section.

Structural roots of 'struggle' and 'fight'

As discussed in Chapter Three, it was evident that some tensions within the domain have their roots in the way the domain is structured and the influences that have shaped it. Despite the rhetoric of partnership and collaboration, there are structural obstacles to joint working between the different public authorities involved in the special needs domain. Little has been done to ensure collaboration with voluntary and community organisations. Although planned legislative changes (HM Government, 2013), including the replacement of the

statement of SEN with an education, health and care plan (EHCP) may address some of these issues there remain difficulties. The lack of structural coherence is multi-faceted and includes separate organisational, accountability and management structures and separate budgetary arrangements as well as the expectations of different professional disciplines. Even if it proves possible to address these issues this will not of itself ensure the special needs domain becomes less adversarial. Problems are likely to continue where children are on the borderline of having needs sufficiently complex to be addressed under the legislation. In addition, policy makers and administrators need to be aware that many of the tensions and struggles experienced by those inhabiting the special needs domain do not stem from structural deficits. These struggles and tensions need to be acknowledged and addressed in other ways.

In Chapter Three I identified a number of influences that have shaped the special needs domain including public policy, changing perceptions of disability, and changes in understanding of what constitutes a special need. Although public policy appears to be based on principles of partnership and collaboration, during the past three decades emphases have varied resulting in uncertainty about what these terms meant in practice. A focus on partnership and joint planning had been exchanged for the adoption of market principles to be replaced by an emphasis on collaborative practice combined with the efficient use of public money. There has been considerable change in public perceptions of disability during this period. At the beginning of the 1970s some children were viewed as ineducable while a neonate disability movement was identifying society as disabling people rather than personal impairment. In the 1981 International Year of Disabled People, the message was to see the person not the disability, and in 2012 we were invited to celebrate the Paralympic Super Heroes. Children are now assessed as having special needs that were either unknown or unrecognised thirty years ago such as AD(H)D, dyspraxia, dyslexia and AS/HFA (Dyson, 1997) and there is an increase in the number of children with complex disabilities entering the school system (Russell, 2008, 2011).

These changes have had consequences. Changes in public policy have not always been accompanied by funding enabling their implementation, as is most evident in the move to developing a more inclusive education system, which could only be achieved by closing special schools and using the funding released to provide enhanced provision in mainstream schools. The result of a policy being implemented before the funding is in place has at times resulted in unsatisfactory and inadequate provision and placed additional pressure on practitioners, children and parents. Decisions may be made on the basis of principle rather than what is in the child's best interests, as when the efficient expenditure of government money, combined with the promotion of inclusive education, makes it difficult to suggest that the best placement for an individual child might be a special school.

The lack of interconnectivity of services can result in failures in communication between practitioners, confusion for parents when practitioners disagree, uncertainty as to who does what, and multiple assessments. At present education and social services are funded through local authorities and health service provision is managed through regional trusts. Despite the development of local authority children's services bringing together education and social work, services tend to continue to be separate with separate budgets. One of the potential obstacles to the successful implementation of EHCPs is whether budgetary obstacles can be overcome in planning coordinated provision.

The experience of 'struggle' and 'fight'

As discussed in Chapters Six, Seven and Eight, some of the tensions experienced by parents and practitioners stem from structural aspects of the special needs domain. Practitioners identified uncertainties about where responsibility lay for decision making, speaking particularly of the difficulties engendered by structural changes and changes in personnel. Parents experienced difficulties if their child's needs required the intervention of public services, finding that even when a course of action was agreed, difficulties could arise due to the lack of appropriate resources or a lack of agency of practitioners. Troubling accounts were related by parents of situations where children experienced lengthy periods out of school, became subject to the criminal justice system, or where the family was subjected to child protection procedures because of lack of resources or lack of agency on the part of practitioners to take appropriate action. Although these tensions could be attributed to aspects of the domain, it was also clear that many areas of tension were experienced as personal issues by both parents and practitioners. Practitioners spoke of feelings of guilt and regret that they had been unable to adequately address the needs of some children. Parents discussed their experience of accepting their child's differences and then coping with those differences in public spaces. The principle areas of struggle identified by participants were in the everyday experiences of living or working with children and young people with AS/HFA. However more serious tensions arose when there were differences in perspective between practitioners and parents. Such disagreements could result in 'fight' and in actions with potential long term consequences for a child with AS/HFA and for their family.

Relating findings to the existing literature

As discussed in Chapter Four, many researchers have explored aspects of the relationship between parents and practitioners in the special needs domain and, in particular, in education more generally. It is perhaps disappointing to find that the power differentials identified by Todd and Higgins (1998) and Bendelow and Brady (2002) continue to be evident in the narratives of the participants in this study. Vincent and Martin (2000, 2002) and Gazeley (2012) use Bourdieusian concepts to explore the dynamics of the struggle between parents

and practitioners, relating such struggles to social class, a concept which is currently subject to some review (Savage et al., 2013). I also use Bourdieusian concepts, focusing on variations in the possession of cultural capital of both parents and practitioners. Amongst participants in this study, it was evident that a parent with an accumulation of cultural capital in relation to special needs could be viewed as a threat by a practitioner with less knowledge of special needs or the mechanics of the special needs domain. Rather than drawing on the knowledge of such parents and establishing a learning partnership to the benefit of the child, such relationships could become adversarial with parents feeling under attack by practitioners and practitioners feeling their professional expertise was being undermined. Such power struggles were described by a number of parents, sometimes using militaristic language.

Whereas many studies focus primarily on parental experience or on relationships between parents and practitioners, this study gathered narrative accounts of the experiences of both practitioners and parents. An interesting and surprising finding is the similarity of the experiences of struggle reported by practitioners and parents, all of whom discussed their personal dilemmas in addressing the needs of children and young people with AS/HFA. Practitioners spoke of a sense of guilt that they had been ill-equipped to support some children, of failure to recognise and differentiate behaviour problems and problems stemming from a child's atypical development, dilemmas about the appropriateness of punishment, fears when children behave inappropriately and put others at risk, and anger that they were sometimes required to withhold information as part of a policy to ration services. All too often practitioners are viewed as personifying the formal structure of service provision, but in this study they are shown to be people who care deeply about the children and young people they come into contact with in their working lives, are affected personally by those young people, and invest their personal time and resources in learning more about the nature and effects of AS/HFA and how to respond more appropriately to young people with these conditions.

Addressing different audiences

This research has relevance to a number of different audiences, including the academic community, those involved in developing and making public policy, practitioners in the special needs domain and the parents of children with special needs.

In my discussion of the theoretical and analytical framework underpinning this study, I have already made a case for exploring further the use of whole *system* approaches, especially in the investigation of complex problem areas. I would add two further points. Firstly, as knowledge progresses, it is possible to lose sight of where ideas originate. Both Bourdieu and Bronfenbrenner, through the work of Kurt Lewin, were influenced in their thinking by Cassirer, but as they belong to different disciplines, the connections between their theoretical

approaches is hidden. Such interconnectivity of ideas is likely to become more difficult to identify as areas of study become increasingly specialised, but the recognition of interconnections of ideas can be enriching. Although specialist knowledge and expertise is essential, I would argue that epistemological eclecticism is also needed in order to create thinkers who are not trapped in their disciplines, but who are able to make connections and develop ideas in different directions.

More specifically in relation to this study, I suggest my findings about the personal responses of practitioners working within the special needs domain adds a further layer of understanding to the nature of tension within that domain. Similarly, the suggestion that conflicts occur more readily between parents with accumulations of cultural capital and less knowledgeable practitioners requires further exploration.

In addressing policy makers and developers, I urge caution in assuming that structural change will diminish adversarial relationships in the special needs domain. The review of the SEN system explicitly identifies its adversarial nature as a driver for change (DfE, 2011, p. 8); implicit in the change agenda is an assumption that changes to the formal structure will reduce parents' sense of having to 'battle' in order for their children's needs to be appropriately addressed. In this thesis, I argue that the adversarial nature of the special needs domain extends far beyond the formal structures and procedures of the SEN system. While I do not claim my sample is representative of all parents and practitioners, many of the difficulties described by the parents and practitioners I interviewed have little to do with formal structures and systems, but are about personal responses, attitudes of the general public, availability of resources, speed and appropriateness of decision making and agency to deliver an appropriate response. The case studies in Chapter Eight demonstrate that even when a course of action is agreed by all concerned and is dealt with using the formal arrangements, it does not mean the action taken is necessarily in the child's best interests or that action can be taken speedily enough. Formal structures are necessary, but they need to be appropriately resourced. Care needs to be taken to ensure individuals do not fall through the cracks, and that if, or when, they do, remedies are speedily applied so as to ensure minimal long term consequences for the child or young person concerned.

Although reforms to the SEN system are expected to reduce some tensions within the special needs domain, some tensions may be exacerbated and new problem areas may emerge as the unintended consequences of change. It is hoped that the reforms will lead to a more coordinated approach to addressing the needs of those disabled children with complex difficulties, but it should be recognised that some children and young people may no longer be considered needy enough to qualify for the new assessment regime, and there may be anxieties as to whether these children's needs will continue to be appropriately addressed. This could include children with AS/HFA, who tend to be diagnosed later than children with

more obvious impairments, and whose difficulties may not require intervention in the early years. In a culture where there is an increasing tendency to think of disability in binary terms, as in the 'strivers/shirkers' rhetoric of politicians and the popular press (Garthwaite, 2011), this could disadvantage those children and young people who appear the same as other children and young people, but who have hidden disabilities. Whilst the celebration of diversity represented by the 2012 Paralympics is welcome, it has done little to benefit those disabled people who require additional support in daily living, and might even be viewed as making life more difficult for some of those now being judged as fit to work, but who previously were in receipt of disability benefits. I have argued elsewhere that focusing on addressing the needs of children and young people with the most complex conditions, as is envisaged in the development of EHCPs, may divert resources from those young people who are perceived as less needy, but whose needs may be exacerbated if not addressed in a timely manner (Thackray, 2012).

Finally, I want to affirm that both practitioners and parents are human beings doing their best for the children and young people in their care, but both are subject to tensions resulting from the situations they find themselves in and the expectations of others. As mentioned in the Postscript to this thesis, parents can find it helpful to understand practitioner perspectives. It is equally important for practitioners to understand parental perspectives and pressures. Although greater mutual understanding may not in itself lead to change, such understanding may facilitate dialogue leading to collaboration rather than argument and distrust. Parents and practitioners have the potential to form communities of practice if both can value the learning and expertise of the other. Such mutual recognition may result in fewer children being side-lined by disagreements between those responsible for their care and support.

The "absent special guest"

Todd (2007) has described the child as "the absent special guest" who is frequently excluded from those discussions that most concern them. Children were not included in this study as the focus of the research was on arriving at a more nuanced understanding of the adversarial nature of the special needs system based on the experience of parents and practitioners. For the reasons outlined in Chapter Five, it was not appropriate to include children in this study, but, children are central to this research as they are those most affected by the tensions present in the special needs domain. The voices of children are present within many of the narratives, even though children were not explicitly included in the study. There is evidence of parents acting in response to their children's expressed needs as when Lynn, Jane and Jenny moved their children to different schools in response to the expressed or enacted wishes of their children. Similarly there is evidence of parents making decisions that are

counter to a child's expressed wishes: Carol suffered considerable discomfort taking Nathan to social gatherings knowing he would act out his discomfort and Sally endured a difficult start at junior school with her son who was resistant to moving to his new school. Although parents may be aware of their children's views, they may disregard them in favour of attempting to fit in with societal expectations. However some parents go out of their way to enable their children's needs to be addressed, as when Naomi re-organised her life and priorities in order to flexi-school her son.

Children, by definition are regarded as vulnerable people in the ethical frameworks and codes of practice of universities and professional research associations. This is not an argument for excluding children from research processes, but it does require thought as to how best to access the voice of children and young people, and consideration of any potential implications for both the child and their carers. Children with special needs are vulnerable both because they are children and because they have needs and requirements that may be different from those of their typically developing peers. Just as some practitioners can adopt paternalistic attitudes in relation to parents, both parents and practitioners may consider children too vulnerable to be allowed a voice. Despite the SEN code of practice clearly stating that children's views should be ascertained, decisions are made contrary to children's wishes, especially when parents argue for a particular course of action.

Even though it may be uncomfortable for adults, consideration must be given to how to ensure the voice of the child is present in research concerning children. Thought needs to be given to areas of potential conflict where there may be a conflict of interests between parents and children. At a time when young people are being given a right to appeal to the Tribunal in relation to the provisions made in their Statements, and presumably EHCPs, the possibility of family conflict cannot be ignored. If the statutory description of the provision to be made for a child includes a residential placement that the child thinks inappropriate and the child appeals and their appeal is upheld contrary to the views of the child's parents, questions arise as to how to ensure the integrity and stability of the family.

Struggle and tension in the special needs domain does affect children. It would be highly appropriate for further research in this area to include the voice of the child, while being aware of the potential problems I have outlined here and in Chapter Five.

Where next?

The purpose of this investigation was to arrive at a more nuanced understanding of what people mean when they use the language of struggle and fight in describing their experiences within the special needs domain. Although the interview data included mentions of good practice and positive relationships between parents and practitioners, this study was

not about collaboration. However, there is scope for further research focusing specifically on the factors that enable collaborative working, both between practitioners and between practitioners and parents. Many studies have focused on the problematic aspects of the special needs domain, perhaps reinforcing the view of the domain as problematic, and studies are needed that identify what works well.

The parents in this study were all women and all but one of the children were boys. Other researchers have discussed the gendered nature of parenting in households with a child with special needs (Gray, 2003, 2006; Green, 2007; Hastings et al., 2005). The possible effects of gender on the experience of both parents and children was not considered in this study, but an investigation that took gender into consideration could further add to understanding of the experience of parenting a child with AS/HFA.

I used Mills' differentiation of public and personal to develop a framework that was used in recognising the blurred boundaries between public and personal. In recent months, this distinction has been used by the broadcast news media in commenting on various social policy issues. I would suggest, the simple binary can all too easily disguise the far more complex and multi-layered nature of problems confronting both individuals and society and that it should be used with caution. The interface between public and personal is interesting and relevant in the current political climate and appropriate for the focus of both theoretical and empirical work.

In conclusion, by using a whole *system* approach, I have made a theoretical contribution to knowledge in combining different theoretical ideas to develop a more nuanced understanding of tension within the special needs domain. In doing so, I have identified a synergy between different disciplinary traditions in questioning Bourdieu's assertion that *field* theory is not a *systems* approach, and in suggesting similarities between the laminated approach of critical realism and *systems* thinking. In addition, I have added to the current understanding of the struggle/fight metaphor by recognising that it is not only parents who struggle, but practitioners working with children with special needs are also confronted by personal dilemmas, some of which are similar to those confronting parents. Further, I suggest that some of the most adversarial relationships occur when parents are more knowledgeable about their child's condition and the systems comprising the special needs domain than the practitioners they engage with.

Postscript

The doctoral journey is much more than an apprenticeship in learning the art (or science) of research and developing some more advanced intellectual and academic skills; it is also a journey of discovery and challenge for the individual. During my journey, I have encountered and overcome a number of problems and have learned things that have subtly changed me and some of my perspectives on life.

Some of the challenges I have encountered were unanticipated, like needing to completely change my research project due to external changes beyond my control. Others were anticipated such as the needing to consider my response to the SEN Green Paper and to other research in areas allied to my own. Perhaps the biggest challenge for me has been the personal one of moving from a position of some scepticism about the value of academic research to inculcating an academic identity into my persona and recognising not only that this does not negate other aspects of who I am, but can enhance the way I view the world and my understanding of the difficulties faced by the parents I aim to support.

It is a November afternoon. I am sitting in a room in a church hall talking to two other women. All three of us have sons on the autism spectrum. Mine is now adult and learning to live independently in a student house. The other two women have sons in the middle years of primary school and one has a younger son, who may also be on the spectrum. We are talking about a meeting one of them had just attended at school. She speaks of the difficulty she was experiencing persuading her son's teacher to accept her son was not the same as other children in his class. There was an acceptance that he was diagnosed with AS/HFA, some strategies had been put in place to help him in with his work, but there was an expectation that he would now no longer have difficulties and would behave and act like the other children in his class. We speak about difference, accepting difference, and the role of schools in normalising and socialising children; we don't use those words, but these are the ideas we talk about and they are ideas that come directly out of my research findings. The other woman is a teacher as well as a parent. She speaks of how her perceptions of children with special needs and behaviour problems have changed because of her own experiences with her own children. Then she says that she also experiences difficulties relating to practitioners when talking about her son; it is as though the fact she is also a teacher provides a common starting point, but because she knows so much about autism, her son's teacher has difficulty knowing how to communicate with her. Our conversation moves on to how a knowledgeable parent can be perceived as a threat by a less knowledgeable practitioner – effectively we are talking about Bourdieusian concepts of cultural capital, habitus and the *field* of struggle…

References

Abbott, D., Morris, J. & Ward, L. (2001). *The Best Place to Be? Policy, Practice and the Experiences of Residential School Placements for Disabled Children*. York: Joseph Rowntree Foundation.

Ackoff, R. L. (1999). On Passing through 80. *Systemic Practice and Action Research, 12*(4), 425-430.

ACPO (2006). *Retention Guidelines for Nominal Records on the Police National Computer*. Winchester, UK: Association of Chief Police Officers for England, Wales and Northern Ireland.

Ahuja, A. S. & Williams, R. (2010). Telling Stories: Learning from Patients' and Families' Experiences of Specialist Child and Adolescent Mental Health Services. *International Journal of Consumer Studies, 34*(5), 603-609.

Ainscow, M. (1995). Education for All: Making It Happen. *Support for Learning, 10*(4), 147-155.

Ajimal, K. S. (1985). Force Field Analysis—a Framework for Strategic Thinking. *Long Range Planning, 18*(5), 55-60.

Alexander, M. C. F. (1848). All Things Bright and Beautiful *Hymns Ancient and Modern*. London: Clowes and Sons Ltd.

Altiere, M. J. & von Kluge, S. (2009). Searching for Acceptance: Challenges Encountered While Raising a Child with Autism. *Journal of Intellectual and Developmental Disability, 34*(2), 142-152.

Altschul, A. T. (1978). A Systems Approach to the Nursing Process. *Journal of Advanced Nursing, 3*, 333-340.

Anderson, S. & Cairns, C. (2011). *The Social Care Needs of Short-Sentence Prisoners*: Revolving Doors Agency.

Angelides, P. & Ainscow, M. (2000). Making Sense of the Role of Culture in School Improvement. *School Effectiveness & School Improvement, 11*(2), 145-163.

Arai, S. M. (2006). Where Does Social Control End and Social Capital Begin? Examining Social Space, Conflict, and the Politics of Difference. *Leisure/Loisir, 30*(2), 329-339.

Ashall, W. (2004). Masculine Domination: Investing in Gender? *Studies in Social and Political Thought, 9*(2), 21-39.

Asperger, H. (1944). Die „Autistischen Psychopathen" Im Kindesalter. *European Archives of Psychiatry and Clinical Neuroscience, 117*(1), 76-136.

Asthana, A. (2010, online). Special Needs Pupils Account for Seven in 10 Permanent Exclusions from School, *The Observer Sunday 19 December*. Retrieved from http://www.guardian.co.uk/education/2010/dec/19/special-needs-permanent-exclusions-school

Atkinson, M., Wilkin, A., Stott, A., Doherty, P. & Kinder, K. (2002). *Multi-Agency Working: A Detailed Study*. Slough: NFER.

Atkinson, P. (1997). Narrative Turn or Blind Alley? *Qualitative Health Research, 7*(3), 325-344.

Atkinson, S. (1994). Rethinking the Principles and Practice of Action Research: The Tensions for the Teacher–Researcher. *Educational Action Research, 2*(3), 238-401.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. et al. (2006). Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: The Special Needs and Autism Project (SNAP). *The Lancet, 368*(9531), 210-215.

Baldwin, W. C., Sauser, B., Boardman, J. & John, L. (2010). A Typology of Systems Paradoxes. *Information Knowledge Systems Management, 9*(1), 1-15.

Banach, M., Iudice, J., Conway, L. & Couse, L. J. (2010). Family Support and Empowerment: Post Autism Diagnosis Support Group for Parents. *Social Work With Groups, 33*(1), 69 - 83.

Baron-Cohen, S. (2002). Is Asperger Syndrome Necessarily Viewed as a Disability? *Focus on Autism and Other Developmental Disabilities, 17*(3), 186-191.

Basit, T. (2003). Manual or Electronic? The Role of Coding in Qualitative Data Analysis. *Educational Research, 45*(2), 143-154.

Batten, A., Corbett, C., Rosenblatt, M., Withers, L. & Yuille, R. (2006). Make School Make Sense - Autism and Education: The Reality for Families Today. London: National Autistic Society.

Becker, H. S. (1967). Whose Side Are We On? *Social Problems, 14*(3), 239-247.

Beckford, N. (2012). Children Held in Police Cells under Mental Health Act. Retrieved 18/11/2012, from http://www.bbc.co.uk/news/uk-20377493

Bendelow, G. & Brady, G. (2002). Experiences of ADHD: Children, Health Research and Emotion Work. In G. Bendelow, M. Carpenter et al. (Eds.), *Gender, Health and Healing: The Public/Private Divide* (pp. 163-180). London: Routledge.

Bennett, E. (2010). Counting the Costs 2010 (p. 12). London: Contact a Family.

Bercow Report. (2008). *A Review of Services for Children and Young People (0-19) with Speech, Language and Communication Needs*. Nottingham: DCSF Crown Copyright.

Bhaskar, R. (2012). *Critical Realism, Interdisciplinarity and Well-Being*. Paper presented at the Social Theory and Health. http://www.palgrave-journals.com/sth/index.html

Bielecki, A. & Stocki, R. (2010). Systems Theory Approach to the Health Care Organization on National Level. *Cybernetics and Systems, 41*(7), 489-507.

Biott, C. (1996). Latency in Action Research: Changing Perspectives on Occupational and Researcher Identities. *Educational Action Research, 4*(2), 169-183.

Blacher, J., Kraemer, B. & Schalow, M. (2003). Asperger Syndrome and High Functioning Autism: Research Concerns and Emerging Foci. *Current Opinion in Psychiatry, 16*(5), 535-542.

Bochner, A. P. (2001). Narrative's Virtues. *Qualitative Inquiry, 7*(2), 131-157.

Borsay, A. (2011). Disability and Education in Historical Perpective. In S. Haines & D. Ruebain (Eds.), *Education, Disability and Social Policy* (pp. 7-21). Bristol, UK: The Policy Press.

Boud, D. & Solomon, N. (2003). "I Don't Think I Am a Learner": Acts of Naming Learners at Work. *Journal of Workplace Learning, 15*(7/8), 326-331.

Boulding, K. E. (1956). General Systems Theory–the Skeleton of Science. *Management Science, 2*(3), 197-208.

Bourdieu, P. (1977). *Outline of a Theory of Practice* (R. Nice, Trans.). Cambridge: Cambridge University Press.

Bourdieu, P. (1985). The Social Space and the Genesis of Groups. *Social Science Information, 24*(2), 195-220.

Bourdieu, P. (1990). *The Logic of Practice* (R. Nice, Trans.). Cambridge: Polity Press.

Bourdieu, P. (1998). *Practical Reason*. Cambridge: Polity Press.

Bourdieu, P. & Wacquant, L. (1992). *An Invitation to Reflexive Sociology*. Cambridge: Polity Press.

Bowlby, J. (1953). *Child Care and the Growth of Love*. London: Pelican.

Branch, W., Pels, R. J., Lawrence, R. S. & Arky, R. (1993). Becoming a Doctor–Critical-Incident Reports from Third-Year Medical Students. *New England Journal of Medicine, 329*(15), 1130-1132.

Brett, J. (2002). The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is It Time for an Alternative Model of Disability? *Disability & Society, 17*(7), 825 - 843.

Bristol, M. M. (1987). Mothers of Children with Autism or Communication Disorders: Successful Adaptation and the Double ABCX Model. *Journal of Autism and Developmental Disorders, 17*(4), 469-486.

Bromley, J., Hare, D. J., Davison, K. & Emerson, E. (2004). Mothers Supporting Children with Autistic Spectrum Disorders: Social Support, Mental Health Status and Satisfaction with Services. *Autism, 8*(4), 409-423.

Bronfenbrenner, U. (1977). Toward an Experimental Ecology of Human Development. *American Psychologist, 32*(7), 513-531.

Bronfenbrenner, U. (1986). Ecology of the Family as a Context for Human Development: Research Perspectives. *Developmental Psychology, 22*(6), 723-742.

Brown, B., Crawford, P. & Darongkamas, J. (2000). Blurred Roles and Permeable Boundaries: The Experience of Multidisciplinary Working in Community Mental Health. *Health & Social Care in the Community, 8*(6), 425-435.

Brown, C. (2010). Cameron Ambushed by Father of Disabled Child, *The Independent*. Retrieved from http://www.independent.co.uk/news/uk/politics/cameron-ambushed-by-father-of-disabled-child-1956151.html

Bruce, E. & Schultz, C. (2002). Non-Finite Loss and Challenges to Communication between Parents and Professionals. *British Journal of Special Education, 29*(1), 9-13.

Brun, C. C., Nicolson, R., Leporé, N., Chou, Y.-Y., Vidal, C. N., DeVito, T. J. et al. (2009). Mapping Brain Abnormalities in Boys with Autism. *Human Brain Mapping, 30*(12), 3887-3900.

Bryman, A. (2008). *Social Research Methods* (Third ed.). Oxford: Oxford Univ Press.

Bryson, C., Elam, G., Gray, M., Pickering, K., Purdon, S., Speight, S. et al. (2008). Development of a Survey on Services for Disabled Children. Nottingham: National Centre for Social Research.

BSA (2002/2004). Statement of Ethical Practice for the British Sociological Association. Retrieved from http://www.britsoc.co.uk/about/equality/statement-of-ethical-practice.aspx

Burgess, R. G. (1984). *In the Field: An Introduction to Field Research*. London: Routledge.

Burgess, R. G. (1988). Conversations with a Purpose: The Ethnographic Interview in Educational Research. In R. G. Burgess (Ed.), *Studies in Qualitative Methodology: A Research Annual* (Vol. 1, pp. 137-155). London: JAI Press.

Burgess-Limerick, T. & Burgess-Limerick, R. (1998). Conversational Interviews and Multiple-Case Research in Psychology. *Australian Journal of Psychology, 50*(2), 63-70.

Burnes, B. & Cooke, B. (2012). Kurt Lewin's Field Theory: A Review and Re-Evaluation. *International Journal of Management Reviews*.

Burr, V. (2003). *Social Constructionism* (Second ed.). London: Routledge.

Calouste Gulbenkian Foundation. (1968). *Community Work and Social Change: A Report on Training*. London: Longman.

Calouste Gulbenkian Foundation. (1973). *Current Issues in Community Work*: Routledge and Kegan Paul.

Chapman, J. (2004). *System Failure* (Second ed.). London: Demos.

Charmaz, K. (2006). *Constructing Grounded Theory*. London: Sage.

Checkland, P. (1999). *Systems Thinking, Systems Practice* (Kindle ed.). Chichester UK: Wiley.

Checkland, P. (2000). Soft Systems Methodology: A Thirty Year Retrospective. *Systems Research & Behavioral Science, 17*, S11-S58.

Checkland, P. & Poulter, J. (2010). Soft Systems Methodology. In M. Reynolds & S. Holwell (Eds.), *Systems Approaches to Managing Change: A Practical Guide* (pp. 191-242). London: Springer.

Clancy, T. R., Effken, J. A. & Pesut, D. (2008). Applications of Complex Systems Theory in Nursing Education, Research, and Practice. *Nursing Outlook, 56*(5), 248-256.

Clandinin, D. J. & Connelly, F. M. (2000). *Narrative Inquiry*. San Francisco: Jossey-Bass.

Clark, J. A. & Mishler, E. G. (1992). Attending to Patients' Stories: Reframing the Clinical Task. *Sociology of Health & Illness, 14*(3), 344-372.

Clark, P. G. (1994). Social, Professional, and Educational Values on the Interdisciplinary Team: Implications for Gerontological and Geriatric Education. *Educational Gerontology, 20*(1), 35 - 51.

Coffield, F. (Ed.). (2000). *The Necessity of Informal Learning*. Bristol: Policy Press.

Cole, B. A. (2005). 'Good Faith and Effort?' Perspectives on Educational Inclusion. *Disability & Society, 20*(3), 331-344.

Coleman, J. S. (1988). Social Capital in the Creation of Human Capital. *American Journal of Sociology, 94*(Supplement), S95-S120.

Cope, J. & Watts, G. (2000). Learning by Doing: An Exploration of Experience, Critical Incidents and Reflection in Entrepreneurial Learning. *International Journal of Entrepreneurial Behaviour & Research, 6*(3), 104-124.

Corbett, J. (1996). *Bad-Mouthing: The Language of Special Needs*. London: Falmer Press.

Corbett, J. & Norwich, B. (1997). Special Needs and Client Rights: The Changing Social and Political Context of Special Educational Research. *British Educational Research Journal, 23*(3), 379-389.

Coyle, J. (1999). Exploring the Meaning of 'Dissatisfaction' with Health Care: The Importance of 'Personal Identity Threat'. *Sociology of Health & Illness, 21*(1), 95-123.

Crawford, T. & Simonoff, E. (2003). Parental Views About Services for Children Attending Schools for the Emotionally and Behaviourally Disturbed (EBD): A Qualitative Analysis. *Child: Care, Health and Development, 29*(6), 481-491.

Creswell, J. W. (2009). Editorial: Mapping the Field of Mixed Methods Research. *Journal of Mixed Methods Research, 3*(2), 95-108.

Cuckle, P. & Bamford, J. (2000). Parents' Evaluation of an Educational Psychology Service. *Educational Psychology in Practice, 16*(3), 361-371.

Daniels, H., Edwards, A., Engeström, Y., Gallagher, T. & Ludvigsen, S. R. (Eds.). (2010). *Activity Theory in Practice: Promoting Learning across Boundaries and Agencies*. London and New York: Routledge.

Davis-Groves, S. A., Barfield, S. T., McCave, E. & Corrigan, S. K. (2007). *Parent Support: Building Structures That Support and Assist Children*. Kansas: University of Kansas School of Social Welfare.

Dempsey, I., Keen, D., Pennell, D., O'Reilly, J. & Neilands, J. (2009). Parent Stress, Parenting Competence and Family-Centered Support to Young Children with an Intellectual or Developmental Disability. *Research in Developmental Disabilities, 30*(3), 558-566.

DES (1978). *Report of the Committee of Inquiry into the Education of Handicapped Children and Young People*. London: HMSO.

DfE (2011). *Support and Aspiration: A New Approach for Special Educational Needs and Disability*. London: The Stationery Office.

DfE (2012a). *Statistical First Release: Special Educational Needs in England, January 2012*. (SFR 14/2012). London: DfE.

DfE (2012b). Support and Aspiration: A New Approach to Special Educational Needs and Disability: Progress and Next Steps. London: Department for Education.

DfEE (1997). *Excellence for All Children: Meeting Special Educational Needs*. London: HMSO.

DFES (2001). *SEN Code of Practice*. Nottingham: DfES Publications.

DfES (2004). *Removing Barriers to Achievement: The Government's Strategy for SEN*. Annesley: DfES Publications.

Dickens, J. (2011). Social Work in England at a Watershed—as Always: From the Seebohm Report to the Social Work Task Force. *British Journal of Social Work, 41*(1), 22-39.

Diez Roux, A. V. (2011). Complex Systems Thinking and Current Impasses in Health Disparities Research. *American Journal of Public Health, 101*(9), 1627-1634.

Directgov (2011). Disability Living Allowance - Eligibility Retrieved 16/10/2011, from http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupp ort/Disabledpeople/DG_10011816

Duncan, N. (2003). Awkward Customers? Parents and Provision for Special Educational Needs. *Disability & Society, 18*(3), 341-356.

Dunsmuir, S., Clifford, V. & Took, S. (2006). Collaboration between Educational Psychologists and Speech and Language Therapists: Barriers and Opportunities. *Educational Psychology in Practice, 22*(2), 125-140.

Dyson, A. (1997). Social and Educational Disadvantage: Reconnecting Special Needs Education. *British Journal of Special Education, 24*(4), 152-157.

Dyson, A. (2001). Special Needs in the Twenty-First Century: Where We've Been and Where We're Going. *British Journal of Special Education, 28*(1), 24-29.

Dyson, A., Farrell, P., Polat, F., Hutcheson, G. & Gallannaugh, F. (2004). *Inclusion and Pupil Achievement*. (RR578). DfES.

Edwards, A., Daniels, H., Gallagher, T., Leadbetter, J. & Warmington, P. (2009). *Improving Inter-Professional Collaborations: Multi-Agency Working for Children's Wellbeing*. London: Routledge.

Edwards, A. & Kinti, I. (2010). Working Relationally at Organisational Boundaries. In H. Daniels, A. Edwards et al. (Eds.), *Activity Theory in Practice: Promoting Learning across Boundaries and Agencies* (pp. 126-139). London and New York: Routledge.

Elder-Vass, D. (2007). Luhmann and Emergentism: Competing Paradigms for Social Systems Theory? *Philosophy of the Social Sciences, 37*(4), 408-432.

Ellingson, L. L. (1998). "Then You Know How I Feel": Empathy, Identification, and Reflexivity in Fieldwork. *Qualitative Inquiry, 4*(4), 492-514.

Ellis, C., Adams, T. E. & Bochner, A. P. (2011). Autoethnography: An Overview. *Forum: Qualitative Social Research (Online Journal), 12*(1). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1589

Elsass, P. M. & Veiga, J. F. (1994). Acculturation in Acquired Organizations: A Force-Field Perspective. *Human Relations, 47*(4), 431-431.

Elsworth, E. (2003). *A Difficult Act to Balance: Partnership between Teachers and Parents of Children with a Disability*. Unpublished Masters Thesis. Christchurch College of Education. Christchurch, NZ.

Emirbayer, M. & Johnson, V. (2008). Bourdieu and Organizational Analysis. *Theory and Society, 37*(1), 1-44.

Eraut, M. (2007). Learning from Other People in the Workplace. *Oxford Review of Education, 33*(4), 403-422.

Fahey, D. K., Carson, E. R., Cramp, D. G. & Muir Gray, J. A. (2004). Applying Systems Modelling to Public Health. *Systems Research and Behavioral Science, 21*(6), 635-649.

Farrell, P., Dyson, A., Polat, F., Hutcheson, G. & Gallannaugh, F. (2007). The Relationship between Inclusion and Academic Achievement in English Mainstream Schools. *School Effectiveness and School Improvement, 18*(3), 335-352.

Farrugia, D. (2009). Exploring Stigma: Medical Knowledge and the Stigmatisation of Parents of Children Diagnosed with Autism Spectrum Disorder. *Sociology of Health & Illness, 31*(7), 1011-1027.

Feinstein, A. (2010). *A History of Autism: Conversations with the Pioneers* (Kindle ed.). Chichester, UK: Wiley-Blackwell.

Field, J. (2003). *Social Capital* (Kindle ed.). London: Taylor & Francis e-Library.

Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook Jr, E. H., Dawson, G., Gordon, B. et al. (1999). The Screening and Diagnosis of Autistic Spectrum Disorders. *Journal of Autism & Developmental Disorders, 29*(6), 439-484.

Finkelstein, V. (2002). The Social Model of Disability Repossessed. *Coalition: the Magazine of the Greater Coalition of Disabled People*, 10-16.

Flanagan, J. C. (1954). The Critical Incident Technique. *Psychological bulletin, 51*(4), 327-358.

Fleischmann, A. (2005). The Hero's Story and Autism: Grounded Theory Study of Websites for Parents of Children with Autism. *Autism, 9*(3), 299-316.

Fombonne, E. (2005). The Changing Epidemiology of Autism. *Journal of Applied Research in Intellectual Disabilities, 18*, 281-294.

Fox, N. J. (2011). Boundary Objects, Social Meanings and the Success of New Technologies. *Sociology, 45*(1), 70-85.

Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics* (Kindle ed.). Chicago: University of Chicago Press.

Frank, A. W. (2000). The Standpoint of Storyteller. *Qualitative Health Research, 10*(3), 354-365.

French, S. (2004a). 'Can You See the Rainbow': The Roots of Denial. In J. Swain, S. French et al. (Eds.), *Disabling Barriers - Enabling Environments* (pp. 81-86). London: Sage.

French, S. (2004b). Disabled Health and Caring Professionals: The Experience of Visually Impaired Physiotherapists. In J. Swain, S. French et al. (Eds.), *Disabling Barriers - Enabling Environments* (pp. 212-218). London: Sage.

Garrett, P. M. (2007). Making Social Work More Bourdieusian: Why the Social Professions Should Critically Engage with the Work of Pierre Bourdieu. *European Journal of Social Work, 10*(2), 225-243.

Garthwaite, K. (2011). 'The Language of Shirkers and Scroungers?' Talking About Illness, Disability and Coalition Welfare Reform. *Disability & Society, 26*(3), 369 - 372.

Gazeley, L. (2012). The Impact of Social Class on Parent–Professional Interaction in School Exclusion Processes: Deficit or Disadvantage? *International Journal of Inclusive Education, 16*(3), 297-311.

Geldard, H. (2004). *Support for Parents with Children Diagnosed with Autism Spectrum Disorders. Are We Getting It Right?* MA Dissertation. School of Health, Community and Education Studies. Northumbria University.

Gherardi, S. & Turner, B. (2002). Real Men Don't Collect Soft Data. In A. M. Huberman & M. B. Miles (Eds.), *The Qualitative Researcher's Companion* (pp. 81-100). London: Sage.

Gillies, V. (2005). Meeting Parents' Needs? Discourses of 'Support' and 'Inclusion' in Family Policy. *Critical Social Policy, 25*(1), 70-90.

Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory*. London: Weidenfeld and Nicolson.

Glazzard, J. & Overall, K. (2012). Living with Autistic Spectrum Disorder: Parental Experiences of Raising a Child with Autistic Spectrum Disorder (ASD). *Support for Learning, 27*(1), 37-45.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity* (Penguin ed.). London: Penguin.

Goodley, D. (2011). *Disability Studies: An Interdisciplinary Introduction*. London: Sage.

Goodley, D., Mclaughlin, J., Runswick-Cole, K. & Campbell, T. (2011). Does Every Child Matter Post-Blair? The Interconnections of Disabled Childhoods: Manchester Metropolitan University/Newcastle University.

Goodley, D. & Runswick-Cole, K. (2011). Problematising Policy: Conceptions of 'Child', 'Disabled' and 'Parents' in Social Policy in England. *International Journal of Inclusive Education, 15*(1), 71 - 85.

Goodley, D. & Tregaskis, C. (2006). Storying Disability and Impairment: Retrospective Accounts of Disabled Family Life. *Qualitative Health Research, 16*(5), 630-646.

Gray, D. E. (1993a). Negotiating Autism: Relations between Parents and Treatment Staff. *Social Science & Medicine, 36*(8), 1037-1046.

Gray, D. E. (1993b). Perceptions of Stigma: The Parents of Autistic Children. *Sociology of Health & Illness, 15*(1), 102-120.

Gray, D. E. (1994). Coping with Autism: Stresses and Strategies. *Sociology of Health & Illness, 16*(3), 275-300.

Gray, D. E. (2002). 'Everybody Just Freezes. Everybody Is Just Embarrassed': Felt and Enacted Stigma among Parents of Children with High Functioning Autism. *Sociology of Health & Illness, 24*(6), 734-749.

Gray, D. E. (2003). Gender and Coping: The Parents of Children with High Functioning Autism. *Social Science & Medicine, 56*, 631-642.

Gray, D. E. (2006). Coping over Time: The Parents of Children with Autism. *Journal of Intellectual Disability Research, 50*(12), 970-976.

Green, J. & Thorogood, N. (2004). *Qualitative Methods for Health Research*. London: Sage.

Green, S. E. (2007). "We're Tired, Not Sad": Benefits and Burdens of Mothering a Child with a Disability. *Social Science & Medicine, 64*(1), 150-163.

Grenfell, M. (2004). *Pierre Bourdieu Agent Provocateur* (Kindle ed.). London: Continuum.

Grenfell, M. (Ed.). (2008). *Pierre Bourdieu - Key Concepts*. Durham: Acumen.

Grunwald, K. & Thiersch, H. (2009). The Concept of the 'Lifeworld Orientation' for Social Work and Social Care. *Journal of Social Work Practice, 23*(2), 131-146.

Hall, P. (2005). Interprofessional Teamwork: Professional Cultures as Barriers. *Journal of Interprofessional Care, 19 Suppl 1*, 188-196.

Haller, B., Dorries, B. & Rahn, J. (2006). Media Labeling Versus the US Disability Community Identity: A Study of Shifting Cultural Language. *Disability & Society, 21*(1), 61-75.

Hallett, G. & Hallett, F. (2011). Editorial. *British Journal of Special Education, 38*(3), 110-111.

Hanafin, J. & Lynch, A. (2002). Peripheral Voices: Parental Involvement, Social Class, and Educational Disadvantage. *British Journal of Sociology of Education, 23*(1), 35-49.

Hardy, C. (2008). Hysteresis. In M. Grenfell (Ed.), *Pierre Bourdieu - Key Concepts* (pp. 131-148). Durham: Acumen.

Hare, D. J., Pratt, C., Burton, M., Bromley, J. & Emerson, E. (2004). The Health and Social Care Needs of Family Carers Supporting Adults with Autistic Spectrum Disorders. *Autism, 8*(4), 425-444.

Harpin, V. (2007). Providing Medical Advice to Support Children with Special Educational Needs. *Paediatrics and Child Health, 17*(12), 467-473.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D. & Remington, B. (2005). Coping Strategies in Mothers and Fathers of Preschool and School-Age Children with Autism. *Autism, 9*(4), 377-391.

Hess, R. S., Molina, A. M. & Kozleski, E. B. (2006). Until Somebody Hears Me: Parent Voice and Advocacy in Special Educational Decision Making. *British Journal of Special Education, 33*(3), 148-157.

HM Government (1970a). *Chronically Sick and Disabled Persons Act*. London: HMSO.

HM Government (1970b). *Education (Handicapped Children) Act*. London: HMSO.

HM Government (1970c). *Local Authority Social Services Act*. London: HMSO.

HM Government (1976). *Education Act*. London: HMSO.

HM Government (1981). *Education Act*. London: HMSO.

HM Government (1990). *National Health Service and Community Care Act*. London: HMSO.

HM Government (1995). *Disability Discrimination Act*. London: HMSO.

HM Government (2001). *Special Educational Needs and Disability Act*. London: HMSO.

HM Government (2004a). *Children Act 2004*. London: HMSO.

HM Government (2004b). *Every Child Matters: Change for Children*. Nottingham.

HM Government (2012a). *Health and Social Care Act*. London: HMSO.

HM Government (2012b). *Welfare Reform Act*. London: HMSO.

HM Government (2013). *Children and Families Bill*. London: TSO.

HM Treasury (2003). *Every Child Matters*. (Cm. 5860). Norwich: TSO.

HM Treasury/DfES (2007). Aiming High for Disabled Children: Better Support for Families. Norwich: Office of Public Sector Information.

HMSO (1968). *Report of the Committee on Local Authority and Allied Personal Social Services (The Seebohm Report)*. (Cmnd. 3703). London: HMSO.

Hodge, N. & Runswick-Cole, K. (2008). Problematising Parent-Professional Partnerships in Education. *Disability & Society, 23*(6), 637-647.

Hodkinson, A. (2012). Illusionary Inclusion - What Went Wrong with New Labour's Landmark Educational Policy? *British Journal of Special Education, 39*(1), 4-11.

Hodkinson, H. (2010). Learning to Work No Longer: Exploring "Retirement". *Journal of Workplace Learning, 22*(1/2), 94-103.

Hodkinson, P., Biesta, G. & James, D. (2007). Understanding Learning Cultures. *Educational Review, 59*(4), 415-427.

Hodkinson, P., Ford, G., Hodkinson, H. & Hawthorn, R. (2008). Retirement as a Learning Process. *Educational Gerontology, 34*(3), 167-184.

Hoggart, R. (1957). *The Uses of Literacy*. London: Chatto & Windus.

Hollis, F. (1964). *Casework: A Psychosocial Therapy*. New York: Random House.

House of Commons Education and Skills Committee (2006). *Special Educational Needs: Third Report of Session 2005-06*. (HC 478-1). London: The Stationery Office.

Housley, W. (1999). Role as an Interactional Device and Resource in Multidisciplinary Team Meetings. *Sociological Research Online, 4*(3).

Housley, W. (2000). Story, Narrative and Team Work. *The Sociological Review, 48*(3), 425-443.

Howitt, C. & Venville, G. (2009). Dual Vision: Capturing the Learning Journey of Pre-Service Early Childhood Teachers of Science. *International Journal of Research and Method in Education, 32*(2), 209-230.

Howlin, P. & Asgharian, A. (1999). The Diagnosis of Autism and Asperger Syndrome: Findings from a Survey of 770 Families. *Developmental Medicine and Child Neurology, 41*(12), 834-839.

Howlin, P. & Moore, A. (1997). Diagnosis in Autism: A Survey of over 1200 Patients in the UK. *Autism, 1*(2), 135-162.

Humphrey, N. & Symes, W. (2010). Perceptions of Social Support and Experience of Bullying among Pupils with Autistic Spectrum Disorders in Mainstream Secondary Schools. *European Journal of Special Needs Education, 25*(1), 77-91.

Hyde, K. L., Samson, F., Evans, A. C. & Mottron, L. (2010). Neuroanatomical Differences in Brain Areas Implicated in Perceptual and Other Core Features of Autism Revealed by Cortical Thickness Analysis and Voxel-Based Morphometry. *Human Brain Mapping, 31*(4), 556-566.

Illingworth, C. & Male, I. (2011). *Don't Believe Everything You Google: Accuracy of Treatment Advice from the Internet and Television for Parents of Children with Autism and Asds*. unpublished research report. Brighton and Sussex Medical School/Nightingale Primary Care Centre. Haywards Heath, UK.

Jackson, B. & Marsden, D. (1966). *Education and the Working Class*. Harmondsworth: Penguin.

Jackson, L. (2002). *Freaks, Geeks and Asperger Syndrome: A User Guide to Adolescence*. London: Jessica Kingsley.

Jackson, M. C. (2000). *Systems Approaches to Management* (Kindle ed.). New York: Kluwer Academic/Plenum.

Jackson, M. C. (2006). Creative Holism: A Critical Systems Approach to Complex Problem Situations. *Systems Research and Behavioral Science, 23*(5), 647-657.

Jackson, M. C. (2009). Fifty Years of Systems Thinking for Management. *Journal of the Operational Research Society, 60*, S24-S32.

Jackson, M. C. & Keys, P. (1984). Towards a System of Systems Methodologies. *Journal of the Operational Research Society, 35*(6), 473-486.

Jackson, R. (2005). The Curious Case of the Warnock Report. *TESS*. Retrieved from http://www.tes.co.uk/article.aspx?storycode=2156612

Jacobs, B. (2004). Using Soft Systems Methodology for Performance Improvement and Organisational Change in the English National Health Service. *Journal of Contingencies and Crisis Management, 12*(4), 138-149.

Jacobs, B. H. (2011). *How Can Autistic Intelligence Be Recognised and Accommodated in an Inclusive Education Framework?* PhD unpublished, Leicester.

Kalim, K., Carson, E. & Cramp, D. (2006). An Illustration of Whole Systems Thinking. *Health Services Management Research, 19*(3), 174-185.

Kanner, L. (1943). Autistic Disturbances of Affective Contact. *Nervous Child, 2*, 217-250.

Keay, D. (1987). Aids, Education and the Year 2000. *Woman's Own,* 8-10.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T. & Gallagher, S. (2010). The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390-397.

King, M. (2009). *Systems, Not People, Make Society Happen*: Holcombe Publishing.

King, M. & Thornhill, C. (2005). *Niklas Luhmann's Theory of Politics and Law*. Basingstoke: Palgrave Macmillan.

Kingsley, E. P. (1987). Welcome to Holland Retrieved 6/03/2010, from http://www.our-kids.org/Archives/Holland.html

Kirby, A., Davies, R. & Bryant, A. (2005). Do Teachers Know More About Specific Learning Difficulties Than General Practitioners? *British Journal of Special Education, 32*(3), 122-126.

Kirschner, S. R. & Lachicotte, W. S. (2001). Managing Managed Care: Habitus, Hysteresis and the End(s) of Psychotherapy. *Culture, Medicine & Psychiatry, 25*(4), 441-456.

Kolb, D. A. (1984). *Experiential Learning*. Englewood Cliffs, NJ: Prentice-Hall.

Konkola, R., Tuomi–Gröhn, T., Lambert, P. & Ludvigsen, S. (2007). Promoting Learning and Transfer between School and Workplace. *Journal of Education and Work, 20*(3), 211-228.

Kral, M. J., Links, P. S. & Bergmans, Y. (2011). Suicide Studies and the Need for Mixed Methods Research. *Journal of Mixed Methods Research*.

Kvale, S. & Brinkmann, S. (2009). *Interviews: Learning the Craft of Qualitative Research Interviewing* (Second ed.). London: Sage.

Lakoff, G. & Johnson, M. (1980a). Conceptual Metaphor in Everyday Language. *Journal of Philosophy, 77*(8), 453-486.

Lakoff, G. & Johnson, M. (1980b). *Metaphors We Live By*. Chicago: University of Chicago Press.

Lamb Inquiry (2009). *Special Educational Needs and Parental Confidence*. Nottingham: DCSF.

Laming, H. (2003). *The Victoria Climbié Inquiry Report*. (Cm. 5370). London: TSO.

Landeros, M. (2011). Defining the 'Good Mother' and the 'Professional Teacher': Parent–Teacher Relationships in an Affluent School District. *Gender and Education, 23*(3), 247-262.

Langan, M. (2011). Parental Voices and Controversies in Autism. *Disability & Society, 26*(2), 193-205.

Larson, E. (1998). Reframing the Meaning of Disability to Families: The Embrace of Paradox. *Social Science & Medicine, 47*(7), 865-875.

Lave, J. (1991). Situating Learning in Communities of Practice. In L. B. Resnick, J. M. Levine et al. (Eds.), *Perspectives on Socially Shared Cognition* (pp. 63-82): American Psychological Association.

Lave, J. & Wenger, E. (1991). *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.

Lave, J., Wenger, E. & Daniels, H. (2005). Practice, Person, Social World *An Introduction to Vygotsky (Second Ed.).* (pp. 149-156). New York, NY US: Routledge.

Leonard, J. (2011). Using Bronfenbrenner's Ecological Theory to Understand Community Partnerships. *Urban Education, 46*(5), 987-1010.

Lewin, K. (1951). *Field Theory in Social Science* (Kindle ed.). New York: Harper and Row.

Lewis, I. & Vulliamy, G. (1980). Warnock or Warlock? The Sorcery of Definitions: The Limitations of the Report on Special Education. *Educational Review, 32*(1), 3-10.

Lord, C., Petkova, E., Hus, V., Gan, W., Lu, F., Martin, D. M. et al. (2012). A Multisite Study of the Clinical Diagnosis of Different Autism Spectrum Disorders. *Archives of General Psychiatry, 69*(3), 306-313.

Luhmann, N. (1992). What is Communication? *Communication Theory, 2*(3), 251-259.

Luhmann, N. (1993). Ecological Communication: Coping with the Unknown. *Systemic Practice and Action Research, 6*(5), 527-539.

Maaranen, K., Kynäslahti, H. & Krokfors, L. (2008). Learning a Teacher's Work. *Journal of Workplace Learning, 20*(2), 133-145.

Macfarlane, B. (2003). Tales from the Front-Line: Examining the Potential of Critical Incident Vignettes. *Teaching Business Ethics, 7*(1), 55-67.

Mackintosh, M. (1992). Partnership: Issues of Policy and Negotiation. *Local Economy, 7*(3), 210-224.

Malcolm, J., Hodkinson, P. & Colley, H. (2003). The Interrelationships between Formal and Informal Learning. *Journal of Workplace Learning, 15*(7/8), 313-318.

Mandell, D. S. & Salzer, M. S. (2007). Who Joins Support Groups among Parents of Children with Autism? *Autism, 11*(2), 111-122.

Mansell, W. & Morris, K. (2004). A Survey of Parents' Reactions to the Diagnosis of an Autistic Spectrum Disorder by a Local Service: Access to Information and Use of Services. *Autism, 8*(4), 387-407.

Marrable, L. F. (2011). *On Needing 'Need': An Exploration of the Construction of the Child with 'Additional Needs'.* DPhil unpublished, University of Sussex.

Marshall, V. & Long, B. C. (2009). Coping Processes as Revealed in the Stories of Mothers of Children with Autism. *Qualitative Health Research, 20*(1), 105-116.

Mason, J. (2006). Mixing Methods in a Qualitatively Driven Way. *Qualitative Research, 6*(1), 9-25.

Maton, K. (2008). Habitus. In M. Grenfell (Ed.), *Pierre Bourdieu - Key Concepts* (pp. 49-65). Durham: Acumen.

Matthews, P. & Hastings, A. (2012). Middle-Class Political Activism and Middle-Class Advantage in Relation to Public Services: A Realist Synthesis of the Evidence Base. *Social Policy & Administration*.

Maxwell, J. A. (2002). Understanding and Validity in Qualitative Research. In A. M. Huberman & M. B. Miles (Eds.), *The Qualitative Researchers Companion* (pp. 37-64). London: Sage.

Maxwell, J. A. (2010). Using Numbers in Qualitative Research. *Qualitative Inquiry, 16*(6), 475-482.

McCartney, E. (1999). Barriers to Collaboration: An Analysis of Systemic Barriers to Collaboration between Teachers and Speech and Language Therapists. *International Journal of Language & Communication Disorders, 34*(4).

McKeever, P. & Miller, K. L. (2004). Mothering Children Who Have Disabilities: A Bourdieusian Interpretation of Maternal Practices. *Social Science & Medicine, 59*(6), 1177-1191.

Melin, L. (1987). The Field-of-Force Metaphor: A Study in Industrial Change. *International Studies of Management & Organization, 17*(1), 24-33.

Merriam, S. B. (1995). What Can You Tell from an N of 1?: Issues of Validity and Reliability in Qualitative Research. *PAACE Journal of Lifelong Learning, 4*, 51-60.

Merrill, B. & West, L. (2009). *Using Biographical Methods in Social Research*. London: Sage.

Mickelson, K. D. (1997). Seeking Social Support: Parents in Electronic Support Groups. In S. Kiesler (Ed.), *Culture of the Internet* (pp. 157-178). Mahwah, NJ: Lawrence Erlbaum Associates.

Midence, K. & O'Neill, M. (1999). The Experience of Parents in the Diagnosis of Autism: A Pilot Study. *Autism, 3*(3), 273-285.

Midgley, G. (1992). The Sacred and Profane in Critical Systems Thinking. *Systemic Practice and Action Research, 5*(1), 5-16.

Midgley, G. (2000). *Systemic Intervention: Philosophy. Methodology, and Practice.* New York: Plenum.

Midgley, G., Munlo, I. & Brown, M. (1998). The Theory and Practice of Boundary Critique: Developing Housing Services for Older People. *Journal of the Operational Research Society, 49*(5), 467-478.

Miller, C. & Ahmad, Y. (2000). Collaboration and Partnership: An Effective Response to Complexity and Fragmentation or Solution Built on Sand? *The International Journal of Sociology and Social Policy, 20*(5/6), 1-38.

Miller, J. & Glassner, B. (2004). The "Inside" and the "Outside": Finding Realities in Interviews. In D. Silverman (Ed.), *Qualitative Research: Theory Method and Practice* (pp. 125-139): Sage Publications Ltd.

Mills, C. W. (1959). *The Sociological Imagination* (Kindle ed.). Oxford: Oxford University Press, Inc.

Mingers, J. (2011). The Contribution of Systemic Thought to Critical Realism. *Journal of Critical Realism, 10*(3).

Mingers, J. & White, L. (2010). A Review of the Recent Contribution of Systems Thinking to Operational Research and Management Science. *European Journal of Operational Research, 207*(3), 1147-1161.

Mishler, E. G. (1984). *The Discourse of Medicine: Dialectics of Medical Interviews*. Norwood, NJ: Ablex.

Mishler, E. G. (1986). *Research Interviewing: Context and Narrative*. Cambridge, Mass: Harvard University Press.

Molloy, H. & Vasil, L. (2002). The Social Construction of Asperger Syndrome: The Pathologising of Difference? *Disability & Society, 17*(6), 659-669.

Moore, R. (2008). Capital. In M. Grenfell (Ed.), *Pierre Bourdieu - Key Concepts* (pp. 101-117). Durham: Acumen.

Morgan, G. (1980). Paradigms, Metaphors, and Puzzle Solving in Organization Theory. *Administrative Science Quarterly, 25*(4), 605-622.

Moriña Díez, A. (2010). School Memories of Young People with Disabilities: An Analysis of Barriers and Aids to Inclusion. *Disability & Society, 25*(2), 163-175.

Muggleton, J. (2012). *Raising Martians: From Crash-Landing to Leaving Home*. London: Jessica Kingsley.

Myers, B. J., Mackintosh, V. H. & Goin-Kochel, R. P. (2009). "My Greatest Joy and My Greatest Heart Ache:" Parents' Own Words on How Having a Child in the Autism Spectrum Has Affected Their Lives and Their Families' Lives. *Research in Autism Spectrum Disorders, 3*(3), 670-684.

Naaldenberg, J., Vaandrager, L., Koelen, M., Wagemakers, A.-M., Saan, H. & de Hoog, K. (2009). Elaborating on Systems Thinking in Health Promotion Practice. *Global Health Promotion, 16*(1), 39-47.

Newbury, J. (2011). Situational Analysis: Centerless Systems and Human Service Practices. *Child & Youth Services, 32*(2), 88-107.

Newton, J. M., Billett, S. & Ockerby, C. M. (2009). Journeying through Clinical Placements - an Examination of Six Student Cases. *Nurse Education Today, 29*(6), 630-634.

NICE (2011). *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum*. London: RCOG.

Nind, M. (2008). Learning Difficulties and Social Class: Exploring the Intersection through Family Narratives. *International Studies in Sociology of Education, 18*(2), 87-98.

Nissenbaum, M. S., Tollefson, N. & Reese, R. M. (2002). The Interpretative Conference: Sharing a Diagnosis of Autism with Families. *Focus on Autism and Other Developmental Disabilities, 17*(1), 30-43.

Noble, G. & Watkins, M. (2003). So, How Did Bourdieu Learn to Play Tennis? Habitus, Consciousness and Habituation. *Cultural Studies, 17*(3-4), 520-539.

Norwich, B. (2010). A Response to 'Special Educational Needs: A New Look'. In L. Terzi (Ed.), *Special Educational Needs: A New Look* (pp. 47-113). London: Continuum.

Nowotny, H. (2005). The Increase of Complexity and Its Reduction: Emergent Interfaces between the Natural Sciences, Humanities and Social Sciences. *Theory, Culture & Society, 22*(5), 15-31.

O'Donoghue, M. (2012). Putting Working-Class Mothers in Their Place: Social Stratification, the Field of Education, and Pierre Bourdieu's Theory of Practice. *British Journal of Sociology of Education*, 1-18.

Ofsted (2010). The Special Educational Needs and Disability Review: A Statement Is Not Enough. Manchester: Ofsted.

Olesen, V. (2000). Feminisms and Qualitative Research at and into the Millenium. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (Second ed., pp. 215-255). Thousand Oaks, CA: Sage.

Oliver, M. (2009). *Understanding Disability: From Theory to Practice* (Second ed.). Basingstoke: Palgrave.

Opie, A. (1997). Thinking Teams Thinking Clients: Issues of Discourse and Representation in the Work of Health Care Teams. *Sociology of Health & Illness, 19*(3), 259-280.

Ortega, F. & Choudhury, S. (2011). 'Wired up Differently': Autism, Adolescence and the Politics of Neurological Identities. *Subjectivity, 4*(3), 323-345.

Osborne, L. A. & Reed, P. (2008). Parents' Perceptions of Communication with Professionals During the Diagnosis of Autism. *Autism, 12*(3), 309-324.

Paradice, R. & Adewusi, A. (2002). 'It's a Continuous Fight Isn't It?': Parents' Views of the Educational Provision for Children with Speech and Language Difficulties. *Child Language Teaching and Therapy, 18*(3), 257-288.

Parsons, S., Lewis, A. & Ellins, J. (2009). The Views and Experiences of Parents of Children with Autistic Spectrum Disorder About Educational Provision: Comparisons with Parents of Children with Other Disabilities from an Online Survey. *European Journal of Special Needs Education, 24*(1), 37-58.

Parsons, T. (1951). *The Social System* (Kindle ed.). London: The Free Press of Glencoe.

Parsons, T. (1961). *Theories of Society* (Kindle ed.). New York: The Free Press of Glencoe.

Peillon, M. (1998). Bourdieu's Field and the Sociology of Welfare. *Journal of Social Policy, 27*(02), 213-229.

Perlman, H. H. (1957). *Social Casework: A Problem-Solving Process*: University of Chicago Press.

Pinkus, S. (2003). All Talk and No Action: Transforming the Rhetoric of Parent–Professional Partnership into Practice. *Journal of Research in Special Educational Needs, 3*(2), 115-121.

Pinkus, S. (2006). Applying a Family Systems Perspective for Understanding Parent–Professional Relationships: A Study of Families Located in the Anglo-Jewish Community. *Support for Learning, 21*(3), 156-161.

Plowden Report (1967). *Children and Their Primary Schools (the Plowden Report)*. London: HMSO.

Popplestone, G. (1971). The Ideology of Professional Community Workers. *British Journal of Social Work, 1*(1), 85-104.

Portes, A. (1998). Social Capital: Its Origins and Applications in Modern Sociology. *Annual Review of Sociology, 24*(1), 1.

Power, E. (2010). *Guerrilla Mum: Surviving the Special Educational Needs Jungle*. London: Jessica Kingsley.

Preston, G. (2005). Helter Skelter: Families, Disabled Children and the Benefit System. London: Centre for Analysis of Social Exclusion London School of Economics.

Prior, L. (2004). Doing Things with Documents. In D. Silverman (Ed.), *Qualitative Research: Theory Method and Practice* (pp. 76-94): Sage Publications Ltd.

Public Accounts Committee (2012). Oversight of Special Education for Young People Aged 16-25. Retrieved from http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1636/163602.htm

Putnam, R. D. (1995). Tuning in, Tuning Out: The Strange Disappearance of Social Capital in America. *Political Science and Politics, 28*(4), 664-683.

Putnam, R. D. (2001). *Bowling Alone: The Collapse and Revival of American Community*: Simon & Schuster.

Quinlan, E. & Quinlan, A. (2010). Representations of Rape: Transcending Methodological Divides. *Journal of Mixed Methods Research, 4*(2), 127-143.

Ramage, M. & Shipp, K. (2009). *Systems Thinkers* (Kindle ed.). London: Springer London.

Ranson, S., Martin, J. & Vincent, C. (2004). Storming Parents, Schools and Communicative Inaction. *British Journal of Sociology of Education, 25*(3), 259-274.

Reay, D. (1998). *Class Work: Mothers' Involvement in Children's Schooling*. London: University College Press.

Reay, D. (2000). A Useful Extension of Bourdieu's Conceptual Framework?: Emotional Capital as a Way of Understanding Mothers' Involvement in Their Children's Education? *The Sociological Review, 48*(4), 568-585.

Reid, B. (2011). We've Got Great Expectations. London: National Autistic Society.

Reynolds, M. (2011). *Bells That Still Can Ring: Systems Thinking in Practice*. Paper presented at the 1st International Workshop on Complex Systems Thinking and Real World Applications, Litchfield Park, AZ.

Reynolds, M. & Holwell, S. (2010). Introducing Systems Approaches. In M. Reynolds & S. Holwell (Eds.), *Systems Approaches to Managing Change: A Practical Guide* (pp. 1-23). London: Springer.

Riessman, C. K. (2002). Narrative Analysis In A. M. Huberman & M. B. Miles (Eds.), *The Qualitative Researcher's Companion* (pp. 217-270): Sage.

Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. London: Sage.

Ritchie, J. & Lewis, J. (Eds.). (2003). *Qualitative Research Practice*. London: Sage.

Ritchie, J. & Spencer, L. (1994). Qualitative Data Analysis for Applied Policy Research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing Qualitative Data* (pp. 173-194). London: Routledge.

Roberts, J. & Whiting, C. (2011). Caregivers of School Children with Epilepsy: Findings of a Phenomenological Study. *British Journal of Special Education, 38*(4), 169-177.

Rogers, C. (2003). The Mother/Researcher in Blurred Boundaries of a Reflexive Research Process. *Auto/Biography, 11*(1&2), 47-54.

Rogers, C. (2007). *Parenting and Inclusive Education: Discovering Difference, Experiencing Difficulty*. Basingstoke: Palgrave.

Rogers, R., Tod, J., Powell, S., Parsons, C., Godfrey, R., Graham-Matheson, L. et al. (2006). Evaluation of the Special Educational Needs Parent Partnership Services in England. Canterbury: Canterbury Christ Church University College.

Rose, J. & Haynes, M. (1999). A Soft Systems Approach to the Evaluation of Complex Interventions in the Public Sector. *Journal of Applied Management Studies, 8*(2), 199-216.

Rosenfield, P. L. (1992). The Potential of Transdisciplinary Research for Sustaining and Extending Linkages between the Health and Social Sciences. *Social Science & Medicine, 35*(11), 1343-1357.

Roulstone, A. & Prideaux, S. (2012). *Understanding Disability Policy*. Bristol, UK: The Policy Press.

Row, S. (2005). *Surviving the Special Educational Needs System: How to Be a 'Velvet Bulldozer'*. London: Jessica Kingsley.

Runswick-Cole, K. (2007a). *Parents as Advocates: The Experiences of Parents Who Register an Appeal with the Special Educational Needs and Disability Tribunal (SENDisT).* PhD unpublished, University of Sheffield.

Runswick-Cole, K. (2007b). 'The Tribunal Was the Most Stressful Thing: More Stressful Than My Son's Diagnosis or Behaviour': The Experiences of Families Who Go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability & Society, 22*(3), 315-328.

Runswick-Cole, K. (2011). Time to End the Bias Towards Inclusive Education? *British Journal of Special Education, 38*(3), 112-119.

Runswick-Cole, K. & Hodge, N. (2009). Needs or Rights? A Challenge to the Discourse of Special Education. *British Journal of Special Education, 36*(4), 198-203.

Russell, F. (2003). The Expectations of Parents of Disabled Children. *British Journal of Special Education, 30*(3), 144-149.

Russell, G., Advocat, J., Geneau, R., Farrell, B., Thille, P., Ward, N. et al. (2012). Examining Organizational Change in Primary Care Practices: Experiences from Using Ethnographic Methods. *Family Practice, 29*(4), 455-461.

Russell, G., Kelly, S. & Golding, J. (2010). A Qualitative Analysis of Lay Beliefs About the Aetiology and Prevalence of Autistic Spectrum Disorders. *Child: Care, Health and Development, 36*(3), 431-436.

Rutter, M. (2005). Aetiology of Autism: Findings and Questions. *Journal of Intellectual Disability Research, 49*(4), 231-238.

Ryan, S. (2010). 'Meltdowns', Surveillance and Managing Emotions; Going out with Children with Autism. *Health & Place, 16*(5), 868-875.

Ryan, S. (2011). [Email - Personal Communication].

Ryan, S. & Runswick-Cole, K. (2009). From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43-53.

Sainsbury, C. (2009). *Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome*. London: Sage.

Salt, T. (2010). *Salt Review: Independent Review of Teacher Supply for Pupils with Severe, Profound and Multiple Learning Difficulties (SLD and PMLD)*. Nottingham: DCSF Crown Copyright.

Samson, F., Mottron, L., Soulières, I. & Zeffiro, T. A. (2012). Enhanced Visual Functioning in Autism: An ALE Meta-Analysis. *Human Brain Mapping, 33*(7), 1553-1581.

Sands, R. G. (1993). "Can You Overlap Here?": A Question for an Interdisciplinary Team. *Discourse Processes, 16*(4), 545-564.

Savage, M., Devine, F., Cunningham, N., Taylor, M., Li, Y., Hjellbrekke, J. et al. (2013). A New Model of Social Class? Findings from the BBBC's Great British Class Survey Experiment. *Sociology, 47*(2), 219-250.

Savin-Baden, M. (2004). Achieving Reflexivity: Moving Researchers from Analysis to Interpretation in Collaborative Inquiry. *Journal of Social Work Practice, 18*(3), 365-378.

Schiff, M. (1992). Social Capital, Labor Mobility, and Welfare. *Rationality and Society, 4*(2), 157-175.

Schutz, A. (1970). *On Phenomenology and Social Relations - Selected Writings*. Chicago: University of Chicago Press.

Scott, J. (2001). *Power*. Cambridge: Polity.

Secretary of State for Education (2012). *Draft Legislation on Reform of Provision for Children and Young People with Special Education Needs*. (Cm 8438). London: The Stationery Office.

Senge, P. M. (1990). *The Fifth Discipline*. London: Random House.

Shah, S. (2007). Special or Mainstream? The Views of Disabled Students. *Research Papers in Education, 22*(4), 425-442.

Shakespeare, T. (2006). *Disability Rights and Wrongs*. London: Routledge.

Shakespeare, T. & Watson, N. (2002). The Social Model of Disability: An Outdated Ideology. *Research in Social Science and Disability, 2*, 9-28.

Sikes, P. (2000). Truth and Lies Revisited. *British Educational Research Journal, 26*(2), 257-270.

Silverman, C. (2012). *Understanding Autism*. Oxford: Princeton University Press.

Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analyzing Talk, Text, and Interaction* (Second ed.): Sage Publications Ltd.

Silverman, D. (Ed.). (2004). *Qualitative Research: Theory, Method and Practice* (Second ed.): Sage Publications Ltd.

Sirota, K. G. (2010). Narratives of Transformation: Family Discourse, Autism and Trajectories of Hope. *Discourse & Society, 21*(5), 544-564.

Sloper, P. (2004). Facilitators and Barriers for Co-Ordinated Multi-Agency Services. *Child: Care, Health and Development, 30*(6), 571-580.

Smith, L. & Daughtrey, H. (2000). Weaving the Seamless Web of Care: An Analysis of Parents' Perceptions of Their Needs Following Discharge of Their Child from Hospital. *Journal of Advanced Nursing, 31*(4), 812-820.

Smith, S. R. (2009). Social Justice and Disability: Competing Interpretations of the Medical and Social Models. In K. Kristiansen, S. Vehmas et al. (Eds.), *Arguing About Disability* (Kindle ed.). London: Routledge.

Snell, S. A. & Rosen, K. H. (1997). Parents of Special Needs Children Mastering the Job of Parenting. *Contemporary Family Therapy, 19*(3), 425-442.

Song, L. (2012). Raising Network Resources While Raising Children? Access to Social Capital by Parenthood Status, Gender, and Marital Status. *Social Networks, 34*(2), 241-252.

Sontag, S. (1979). *Illness as Metaphor*. London: Allen Lane.

Sousa, A. C. (2011). From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities. *Symbolic Interaction, 34*(2), 220-243.

Stanley, L. (1992). *The Auto/Biographical I*. Manchester: Manchester University Press.

Stanley, L. (1993). On Auto/Biography in Sociology. *Sociology, 27*(1), 41-52.

Starr, E. M. & Foy, J. B. (2010). In Parents' Voices: The Education of Children with Autism Spectrum Disorders. *Remedial and Special Education*.

Swick, K. J. & Williams, R. D. (2006). An Analysis of Bronfenbrenner's Bio-Ecological Perspective for Early Childhood Educators: Implications for Working with Families Experiencing Stress. *Early Childhood Education Journal, 33*(5), 371-378.

Sykes, A. J. M. (1965). Myth and Attitude Change. *Human Relations, 18*(4), 323-337.

Symes, W. & Humphrey, N. (2011). The Deployment, Training and Teacher Relationships of Teaching Assistants Supporting Pupils with Autistic Spectrum Disorders (ASD) in Mainstream Secondary Schools. *British Journal of Special Education, 38*(2), 57-64.

Taber, N. (2010). Institutional Ethnography, Autoethnography, and Narrative: An Argument for Incorporating Multiple Methodologies. *Qualitative Research, 10*(1), 5-25.

Talbot, J. & Riley, C. (2007). No One Knows: Offenders with Learning Difficulties and Learning Disabilities. *British Journal of Learning Disabilities, 35*(3), 154-161.

Tarakeshwar, N. & Pargament, K. I. (2001). Religious Coping in Families of Children with Autism. *Focus on Autism and Other Developmental Disabilities, 16*(4), 247-260.

Terzi, L. (Ed.). (2010). *Special Educational Needs: A New Look* (Second ed.). London: Continuum.

Thackray, L. (1983). *Borough Associations for Disabled People in Five London Boroughs.* Unpublished MSc, Cranfield Institute of Advanced Technology, Cranfield.

Thackray, L. (2012). *Support and Aspiration: The Costs and Benefits of Changing the Special Needs System.* Paper presented at the EASP/SPA Annual Conference, York.

The Children's Society (2011). 4 in Every 10: Disabled Children Living in Poverty. London: The Children's Society.

The Open University (2002a). *Systems Thinking and Practice: A Primer*. Milton Keynes: The Open University.

The Open University (2002b). *T205 Systems Thinking: Principles and Practice*. The Open University. Milton Keynes.

The Open University (2003). *T205 Systems Thinking: Principles and Practice Course Guide*. Milton Keynes: The Open University.

Thomas, C. (1999). *Female Forms: Experiencing and Understanding Disability*. Buckingham, UK: Open University Press.

Thomas, C. (2004). How Is Disability Understood? An Examination of Sociological Approaches. *Disability & Society, 19*(6), 569-583.

Thomas, C. (2007). *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave.

Thomas, C. (2010). Negotiating the Contested Terrain of Narrative Methods in Illness Contexts. *Sociology of Health & Illness, 32*(4), 647-660.

Thomson, P. (2008). Field. In M. Grenfell (Ed.), *Pierre Bourdieu - Key Concepts* (pp. 67-81). Durham: Acumen.

Timimi, S., Gardner, N. & McCabe, B. (2011). *The Myth of Autism*. Basingstoke, UK: Palgrave Macmillan.

Todd, E. S. (2000). *The Problematic of Partnership in the Assessment of Special Educational Needs.* PhD thesis, University of Newcastle.

Todd, E. S. & Higgins, S. (1998). Powerlessness in Professional and Parent Partnerships. *British Journal of Sociology of Education, 19*(2), 227-236.

Todd, L. (2007). *Partnerships for Inclusive Education: A Critical Approach to Collaborative Working* (Kindle ed.): RoutledgeFalmer.

Todd, L. (2011). Multi-Agency Working and Disabled Children and Young People: From 'What Works' to 'Active Becoming'. In S. Haines & D. Ruebain (Eds.), *Education, Disability and Social Policy* (pp. 65-87). Bristol, UK: The Policy Press.

Todd, S. & Jones, S. (2003). 'Mum's the Word!': Maternal Accounts of Dealings with the Professional World. *Journal of Applied Research in Intellectual Disabilities, 16*(3), 229-244.

Tomlinson, S. (2012). The Irresistible Rise of the SEN Industry. *Oxford Review of Education*, 1-20.

Townsend, P. (1957). *The Family Life of Old People: An Inquiry in East London*: Routledge.

Traustadottir, R. (1991). Mothers Who Care: "Gender, Disability, and Family Life". *Journal of Family Issues, 12*(2), 211-228.

Truss, C. (2008). Peter's Story: Reconceptualising the UK SEN System. *European Journal of Special Needs Education, 23*(4), 365 - 377.

Tsoukas, H. (1998). Introduction: Chaos, Complexity and Organization Theory. *Organization, 5*(3), 291-313.

Tunali, B. & Power, T. G. (2002). Coping by Redefinition: Cognitive Appraisals in Mothers of Children with Autism and Children without Autism. *Journal of Autism and Developmental Disorders, 32*(1), 25-34.

Tveit, A. D. (2009). A Parental Voice: Parents as Equal and Dependent – Rhetoric About Parents, Teachers, and Their Conversations. *Educational Review, 61*(3), 289-300.

Ulrich, W. (2000). Reflective Practice in the Civil Society: The Contribution of Critically Systemic Thinking. *Reflective Practice, 1*(2), 247-268.

UNESCO (1994). The Salamanca Statement and Framework for Action. Salamanca, Spain: World Conference on Special Needs Education: Access and Quality.

United Nations (2007). The Convention on the Rights of Persons with Disabilities Retrieved 2 April 2012, from http://www.un.org/disabilities/convention/about.shtml

van Hove, G., de Schauwer, E., Mortier, K., Bosteels, S., Desnerck, G. & van Loon, J. (2009). Working with Mothers and Fathers of Children with Disabilities: Metaphors Used by Parents in a Continuing Dialogue. *European Early Childhood Education Research Journal, 17*(2), 187-201.

Vehmas, S., Kristiansen, K. & Shakespeare, T. (2009). Introduction: The Unavoidable Alliance of Disability Studies and Philosophy. In K. Kristiansen, S. Vehmas et al. (Eds.), *Arguing About Disability* (Kindle ed.). London: Routledge.

Vehmas, S. & Mäkelä, P. (2009). The Ontology of Disability and Impairment. In K. Kristiansen, S. Vehmas et al. (Eds.), *Arguing About Disability* (Kindle ed.). London: Routledge.

Vincent, C. (2001). Social Class and Parental Agency. *Journal of Education Policy, 16*(4), 347-364.

Vincent, C. & Martin, J. (2000). School-Based Parents' Groups - a Politics of Voice and Representation? *Journal of Education Policy, 15*(5), 459-480.

Vincent, C. & Martin, J. (2002). Class, Culture and Agency: Researching Parental Voice. *Discourse: Studies in the Cultural Politics of Education, 23*(1), 108-127.

von Bertalanffy, L. (1950). An Outline of General System Theory. *The British Journal for the Philosophy of Science, 1*(2), 134-165.

von Bertalanffy, L. (1972). The History and Status of General Systems Theory. *Academy of Management Journal, 15*(4), 407-426.

Warnock, M. (2010). Special Educational Needs: A New Look. In L. Terzi (Ed.), *Special Educational Needs: A New Look* (pp. 11-45). London: Continuum.

Watson, D., Townsley, R. & Abbott, D. (2002). Exploring Multi-Agency Working in Services to Disabled Children with Complex Healthcare Needs and Their Families. *Journal of Clinical Nursing, 11*(3), 367-375.

Waugh, E. (undated). *Home-Life of the Lancashire Factory Folk During the Cotton Famine* (Kindle ed.): Peter Moulding.

Webster, R. & Blatchford, P. (2013). *Making a Statement Project: Final Report*. London: Institute of Education, University of London.

Weick, K. E. (1976). Educational Organizations as Loosely Coupled Systems. *Administrative Science Quarterly, 21*(1), 1-19.

Weinstein, M., Ben-Sira, L., Levy, Y., Zachor, D. A., Itzhak, E. B., Artzi, M. et al. (2011). Abnormal White Matter Integrity in Young Children with Autism. *Human Brain Mapping, 32*(4), 534-543.

Wenger, E. (1998). *Communities of Practice: Learning, Meaning, and Identity*. Cambridge: Cambridge University Press.

Whitaker, P. (2002). Supporting Families of Preschool Children with Autism: What Parents Want and What Helps. *Autism, 6*(4), 411-426.

White, L. (2000). Changing the "Whole System" in the Public Sector. *Journal of Organizational Change Mangement, 13*(2), 162-177.

Wilkinson, L. (2010). School-Age Children with Autism Spectrum Disorders: Screening and Identification. *European Journal of Special Needs Education, 25*(3), 211-223.

Willey, L. H. (1999). *Pretending to Be Normal: Living with Asperger's Syndrome*. London: Jessica Kingsley.

Williams, T., Lamb, B., Norwich, B. & Peterson, L. (2009). Special Educational Needs Has Outlived Its Usefulness: A Debate. *Journal of Research in Special Educational Needs, 9*(3), 199-217.

Willmott, P. & Young, M. (1960). *Family and Class in a London Suburb*. London: Routledge and Kegan Paul.

Wing, L. (1981). Asperger's Syndrome: A Clinical Account. *Psychological Medicine, 11*(1), 115-129.

Woodgate, R. L., Ateah, C. & Secco, L. (2008). Living in a World of Our Own: The Experience of Parents Who Have a Child with Autism. *Qualitative Health Research, 18*(8), 1075-1083.

Woods, P. (1993). Critical Events in Education. *British Journal of Sociology of Education, 14*(4), 355-371.

Wynne, A. (1988). Accounting for Accounts of the Diagnosis of Multiple Sclerosis. In S. Woolgar (Ed.), *Knowledge and Reflexivity* (pp. 101-122). London: Sage.

Yeatman, A. (2004). Social Policy, Freedom and Individuality. *Australian Journal of Public Administration, 63*(4), 80-89.

Yeatman, A. (2011). *Individualised Citizenship and the Welfare State: A Theoretical Account*. Paper presented at the SASS Social Science Forum, University of Brighton.

Young, M. & Willmott, P. (1957). *Family and Kinship in East London*. London: Pelican.

Yuan, S. (2003). Seeing with New Eyes: Metaphors of Family Experience. *Mental Retardation, 41*(3), 207-211.

Appendices

Appendix A

Mapping the Special Needs Domain

As part of the second stage of the research cycle a number of diagrams were produced exploring different aspects of the special needs domain. Most of these diagrams are not included in the body of the thesis as they have informed the research process rather than being research findings. There is a paucity of visual models of the special needs domain and these diagrams may be of value in filling that gap, or providing a platform for developing further visual models. In order to assist this, I have included not only the diagrams, but some notes on the process by which they were created.

Simplified overview of special needs domain (Figure 16)

This diagram represents a simplified representation of the special needs domain, including its constituent parts and some of the influences shaping it. It was drawn following most of the other diagrams in this Appendix but it could also provide a starting point for thinking about scoping projects within the special needs domain.
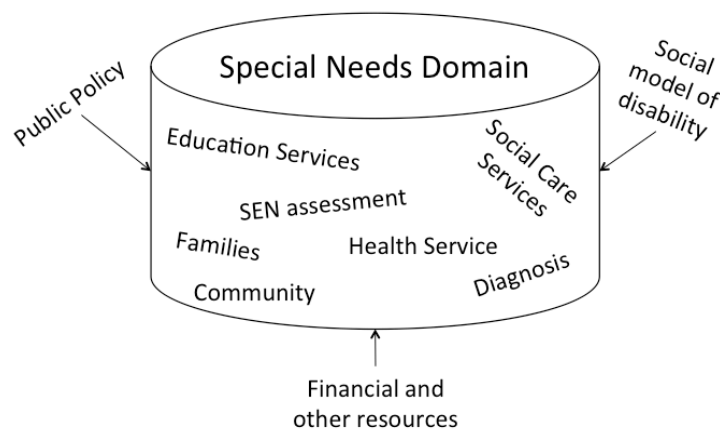

Figure 16 The Special Needs System - constituent parts and influences

Although there are a number of textual descriptions of the domain, including those found in the SEN Toolkit (DfES, 2001), publications aimed at parents (Power, 2010; Row, 2005), and on many websites, there is a notable absence of accessible visual guides to the domain. I found only one diagrammatic representation of the special needs domain in print (Truss, 2008, p. 373), and this was specific to the SEN system. Although this diagram provided a useful starting point, I considered it an over-simplification, placing too much emphasis on the legal domain and ignoring other parts of the special needs domain.

Sensing the domain – spray diagram (Figure 17)

In order, to gain a better understanding of the domain, I created a spray diagram, based on my experience of the domain as a parent and in my previous professional roles, together with what I had learned about the domain from my reading and through discussion with parents and practitioners.
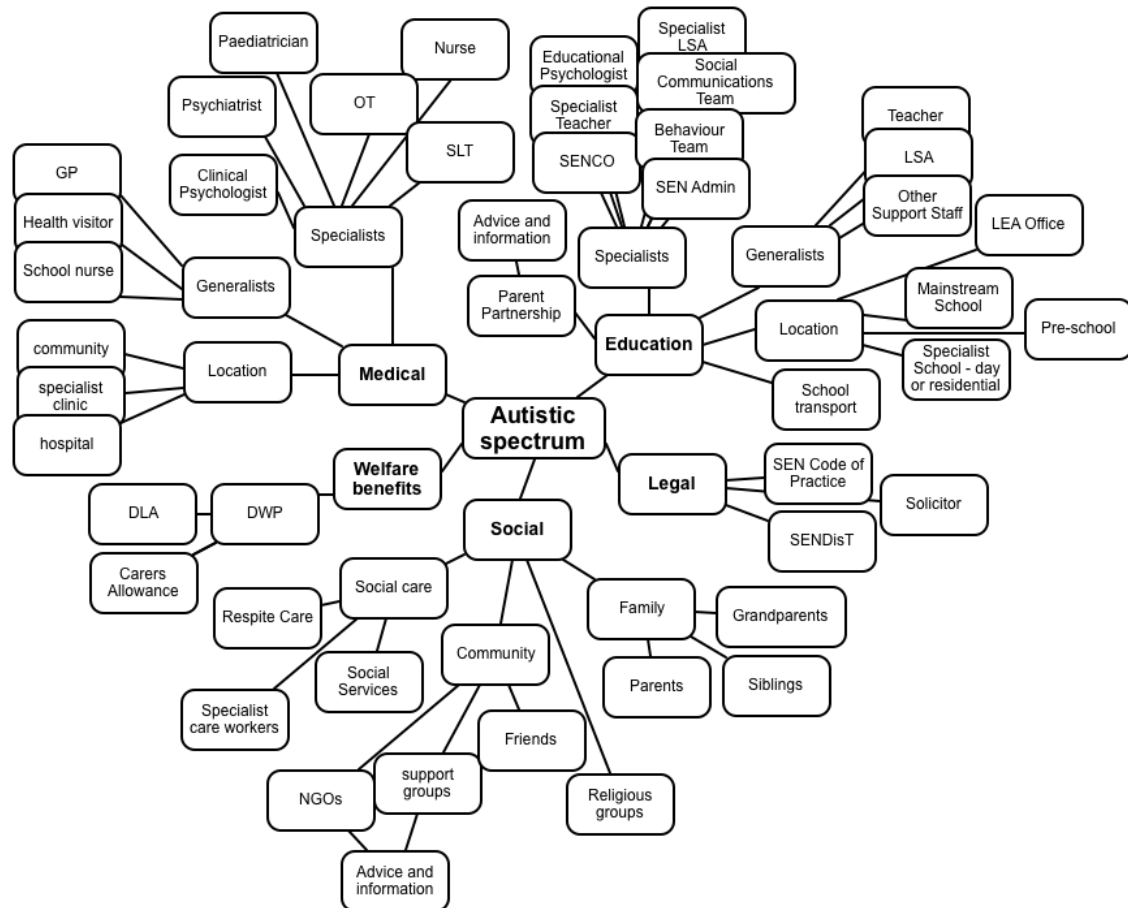

Figure 17 Spray diagram of key features of special needs domain, centres
on autism spectrum

I was able to discuss my spray diagram with Katie Truss and she acknowledged some of her early representations of the SEN system were not dissimilar to my spray diagram. We agreed that whereas a spray diagram is useful for exploring a system, it is less useful in presenting a model of the system. She had sought clarity in her diagram, and that was the next stage in my diagramming process. However the spray diagram did provide a useful tool for informal discussion with parents and practitioners and those discussions identified some of the gaps and areas of confusion in this initial diagram.

Structural diagram of the special needs domain (Figure 18)

The next stage was to develop a structural diagram of the special needs domain. This diagram went through a number of iterations, early versions incorporating a financial sub-domain.
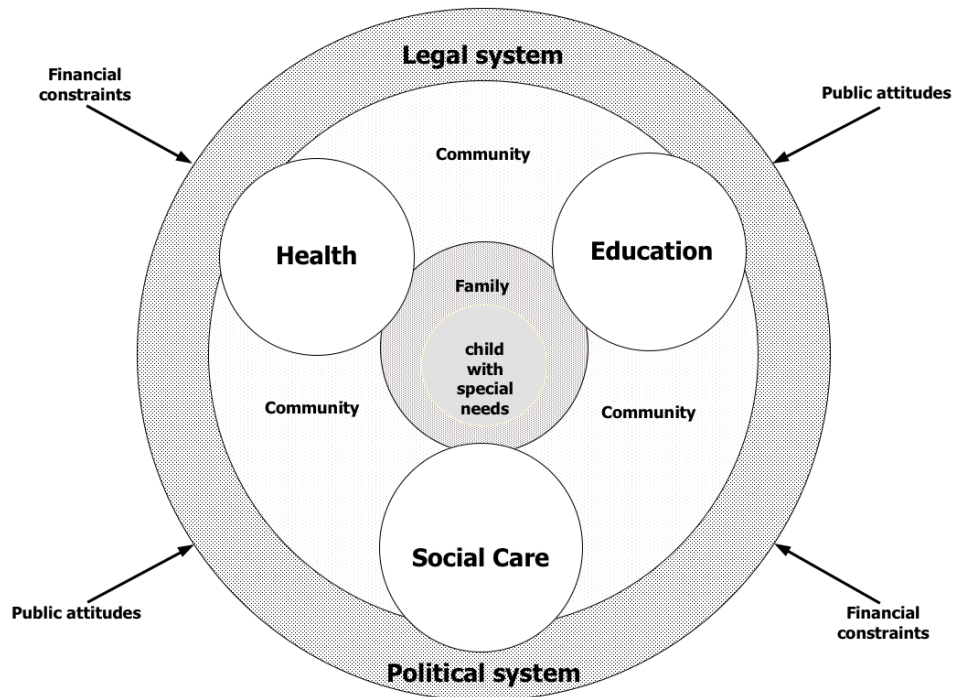

Figure 18 Structural overview of the special needs domain

This diagram proved particularly useful as it clarified that the special needs domain as a structure was the same, whether the diagram placed a child with autism at the centre or a child with any other type of special need. It also provided an avenue to viewing the special needs domain both as a system and as a field structure, as discussed in Chapter Three of the body of the thesis.

Determining the elements to include in the diagram proved challenging. The financial subdomain was removed at an early stage as it confused the financial constraints on the domain, the financial support available to families with a child with special needs and the costs a family might incur in providing for the needs of a child with special needs, additional to those of a family with 'typically developing' children.

The structural diagram showed the structure of the special needs domain, but it says nothing about its functionality, so the next stage was to develop a systems map.

Systems maps of the special needs domain (Figures 19 and 20)

The systems maps shown here were developed out of a series of diagrams exploring the different subdomains of the special needs domain. These diagrams can be accessed on my wiki (http://lizit.pbworks.com/w/page/33034112/Diagramming%20the%20autistic%20spectrum%20domain%20systems).

The first of the systems maps (Figure 19) is a functional overview of the special needs domain showing its various subsystems.
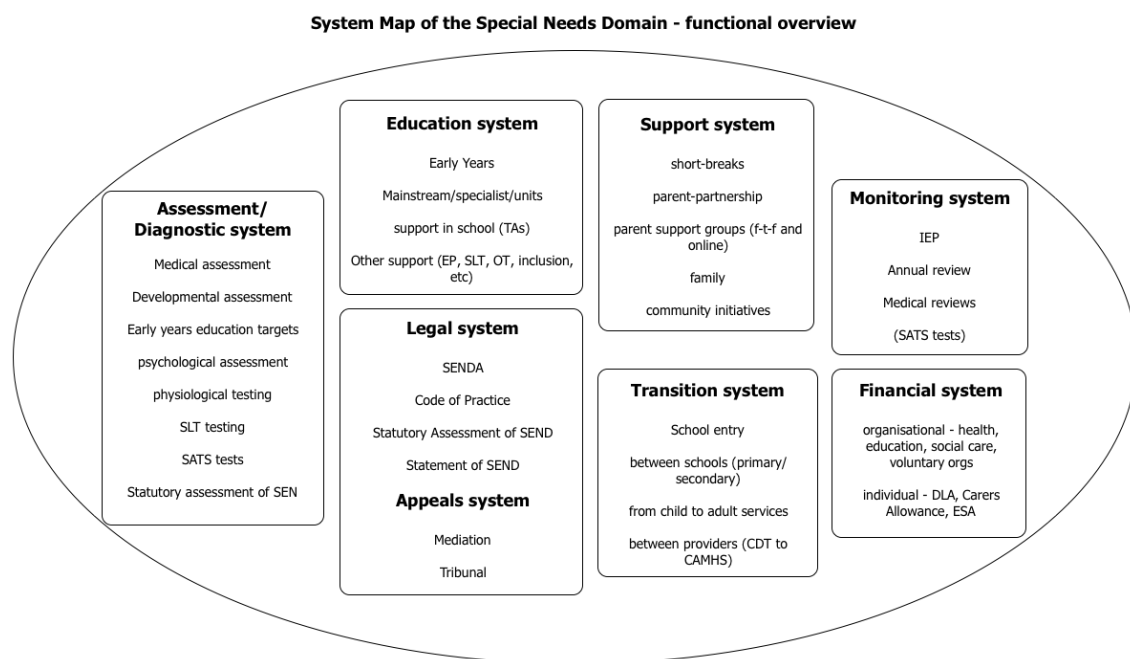

Figure 19 System map showing a functional overview of the subsystems comprising the special needs domain

The second systems map focuses on the interrelationship between the medical and educational assessment systems (Figure 20).
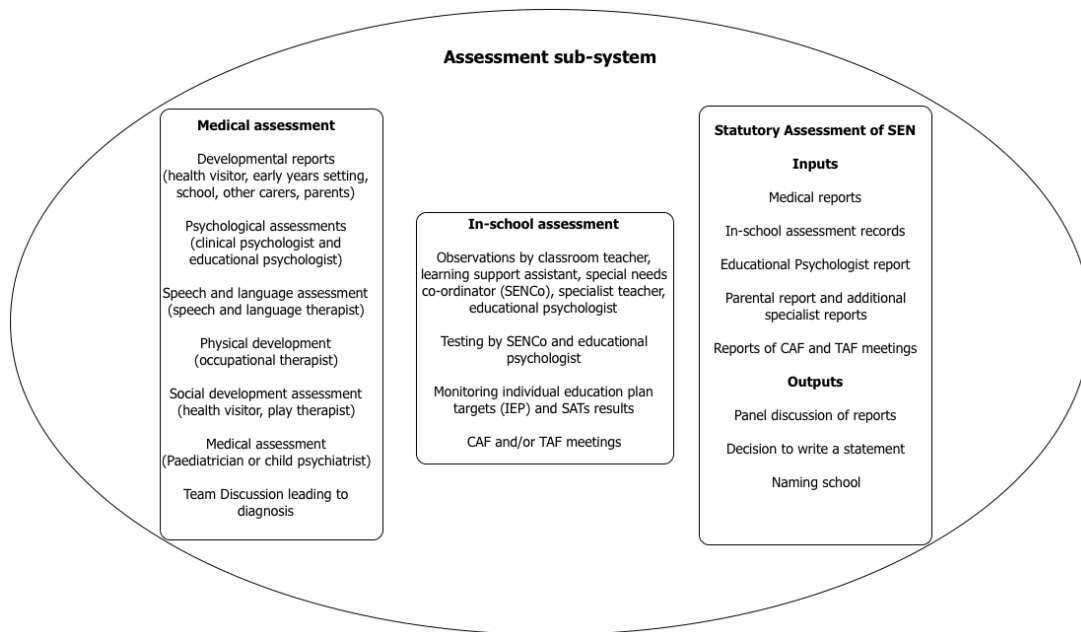
Figure 20 The assessment sub-system of the special needs domain

DfES. (2001). *Special Needs Toolkit*. London: HMSO.

Power, E. (2010). *Guerrilla Mum: Surviving the Special Educational Needs Jungle*. London: Jessica Kingsley.

Row, S. (2005). *Surviving the Special Educational Needs System: How to Be a 'Velvet Bulldozer'*. London: Jessica Kingsley.

Truss, C. (2008). Peter's Story: Reconceptualising the UK SEN System. *European Journal of Special Needs Education, 23*(4), 365 - 377.

Appendix B

The Special Educational Needs System

The SEN system is described in the SEN Code of Practice (DFES, 2001a). The government has indicated that the current code of practice will be revised following the enactment of legislation following the current review of SEN and disability. These notes are a very brief summary of the provision.

At present, the SEN system exists to ensure children with SEN and disabilities receive appropriate support in accessing education. It is recognised that some children with special needs require support from specialists, for example, speech and language therapists. This is provided for in the code of practice, even though the service is provided by health service practitioners, not educationalists, and, in practice, speech and language therapists may devise a programme which is delivered by teaching staff or LSAs.

The SEN system has three tiers:

School Action – the needs of the child are addressed within the school, using school resources and the costs are met from the school budget.

School Action Plus – the needs of the child are addressed within the school with support from external specialists, including specialist staff employed by the local authority and other specialists. Again, the costs are met from the school budget.

Statement of SEN and disability – when a child's needs cannot be met through in-school resources with specialist support, a request can be made to the local authority to make a statutory assessment of SEN and disability. If the request is agreed, the local authority requests reports and information from parents, educational psychologist, school, health services and any other agency that has been involved in supporting the child. Parents may request the local authority to ask for advice from specific people and can include privately obtained assessment reports in the information they submit. Once the information has been collated, a decision is taken to either write a proposed statement or to issue a note in lieu of a statement. Parents either agree the proposed statement and state the school they wish their child to attend, or enter into negotiation with the local authority to ensure the wording of the statement more appropriately addresses their child's needs.

Appeals and mediation systems are in place should it prove impossible for parents and local authority to reach agreement.

DFES (2001). S*EN Code of Practice*. Nottingham: DfES Publications.

Appendix C

US
University of Sussex

Information for Participants

A study of the learning journeys of those involved in providing care and support to children and young people on the autistic spectrum

You are invited to participate in a research study about how different people involved in providing care and support to children and young people on the autistic spectrum have acquired their knowledge about the autistic spectrum.

I am the parent of a young man with Aspergers Syndrome. During the time my son has been growing up, I have had involvement with many professionals in health, education and social services as well as receiving support from voluntary organisations and from other parents through both online forums and real life support groups. For several years I have co-ordinated a support group in my own locality and have observed at first hand the trials and tribulations of parents with a child with 'special needs' and the benefits of sharing experiences and knowledge with other parents. Currently, I am studying for a research degree at the University of Sussex.

This research study is gathering data about the learning journeys of different people involved in providing care and support to children and young people on the autistic spectrum. I will be investigating how different people have developed their knowledge base about the autistic spectrum. I am particularly interested in the different types of learning people have engaged in, for example, medical professionals and teachers learning from their involvement with young people and their carers, or parents learning from each other or by attending training courses.

Research participants are being recruited from amongst parents of children and young people on the autistic spectrum, learning support assistants, residential social care staff, medical students, doctors, health professionals, teachers and others. The study has a number of different aspects and you are invited to be interviewed about your learning experiences and developing knowledge and understanding of autistic spectrum conditions and the support available from various sources.

Other participants are being invited to keep a journal of their learning experiences relating to the autistic spectrum.

I intend to analyse the data obtained from the different sources to discover the common factors in the learning journeys of different participants, and where they differ. By having a better understanding of how people gain their knowledge about the spectrum and the different types of knowledge people have, it may be possible to develop more effective partnerships in supporting children and young people on the spectrum.

The results of the study will be disseminated through conference papers, journal articles and other appropriate means, and will form the basis of my doctoral thesis. I would be happy to send you a copy of the summary of the study outcomes – please include your email address on the participant details form.

If you have any questions about the research study, I will be very happy to answer them. The project is being supervised by Dr Judith Good (j.good@sussex.ac.uk) and Dr Susie Scott (s.scott@sussex.ac.uk) at the University of Sussex.

Liz Thackray
DPhil student
University of Sussex

e.thackray@sussex.ac.uk

Appendix D

US

University of Sussex

Consent Form for Project Participants

A study of the learning journeys of those involved in providing care and support to children and young people with on the autistic spectrum

I agree to take part in the above University of Sussex research project. I have had the project explained to me and I have read and understood the Information for Participants document, which I may keep for my records.

I understand that agreeing to take part means that I am willing to:

- Be interviewed by the researcher
- Allow the interview to be audio recorded
- Make myself available for a further interview should that be required

I understand that any information I provide is confidential. Any data I provide which is used in the final report of this project or in further publications will be anonymised so that individuals referred to cannot be identified.

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

If I have any questions, I understand I can ask Liz Thackray, Researcher (e.thackray@sussex.ac.uk) at any time, or the Project Supervisors Dr Judith Good (j.good@sussex.ac.uk) or Dr Susie Scott (s.scott@sussex.ac.uk).

Name:

Signature:

Date:

Appendix E

Learning Journeys – Participant details

Please complete the following information:

Gender   Male   Female

Age   under 30   31 - 45   46 – 60   Over 60

**What is the highest level at which
you have studied? (e.g. GCSE, A
level, NVQ 3, degree, etc.)**

What is your occupation?

**How did you become interested
in autism?**
(e.g. family member or friend with
an autistic spectrum disorder, work,
etc.)
If you have a child or children on the autistic spectrum:

- How old are they now?

- How old were they when
diagnosed?

- What is their diagnosis?

Ethnicity

White British   White Other

Asian Indian   Asian Pakistani   Asian   Asian Chinese   Asian Other
                                                 Bangladeshi

Black African   Black Caribbean   Black Other

Mixed   Other   Not disclosed

If you would like to receive a summary of the results of this research please provide an email
address:

Appendix F

Interview Schedule

In order to prepare for the interviews I developed a spray diagram (Figure 21), identifying the main themes which I hoped to cover in the interview.
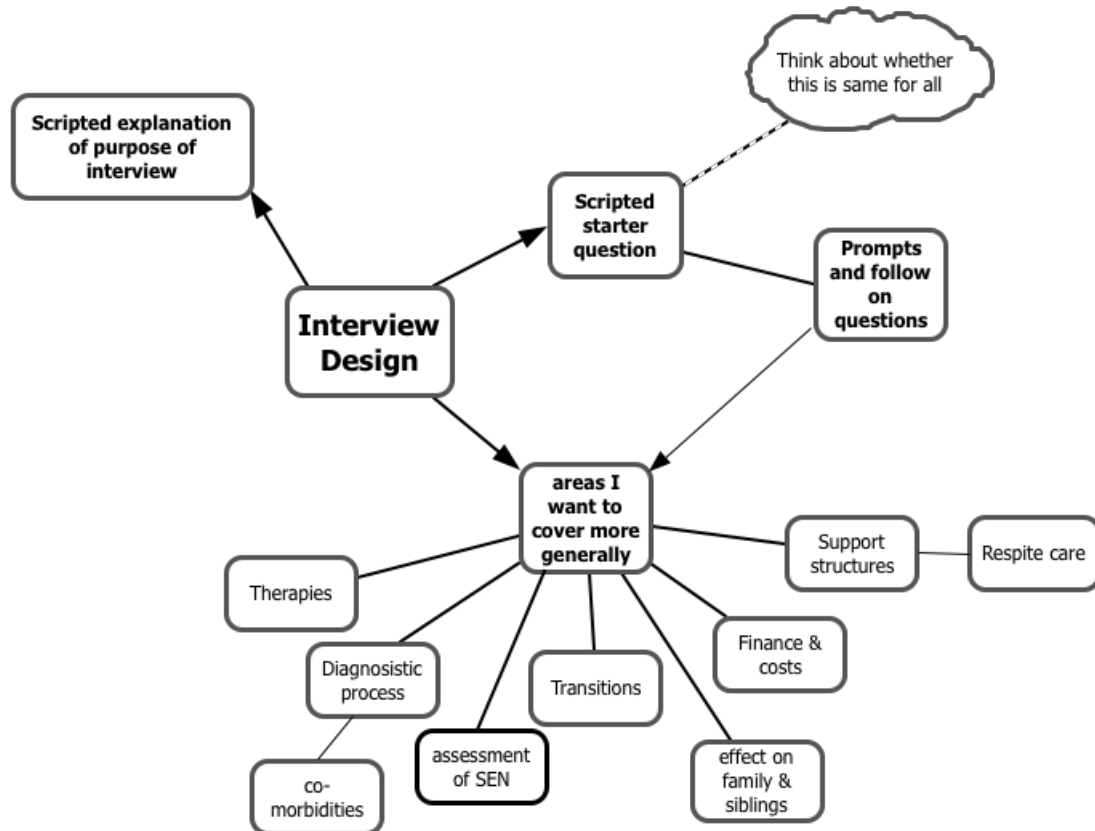

Figure 21 Interview design - Themes

Prior to the interview, I also prepared some questions to use as necessary to encourage conversation. The questions prepared for the interviews at the residential specialist school were:

- What was you experience of autism prior coming to work at [name of school]?
- Thinking back, can you recall any incidents when you either increased your understanding of autism or felt you needed to learn more? (Prompts: what did you learn? What triggers? How did you learn?
- Since being at [name of school], what would you say you have learned about autism?

Appendix G

Example of interview summary

Sarah – clinical psychologist

Sarah is an experienced clinical psychologist working in child and adolescent mental health service (CAMHS) in the south of England. I contacted her on the suggestion of a colleague in the Open University network.

During the interview we discussed a number of different topics including Sarah's own background and training, the parent-professional relationship, intra-agency and interagency relationships and the 2011 Green Paper. From my perspective, I appreciated Sarah's candour and I found it valuable hearing her perspective on how the system works.

Despite the problems Sarah identified with the system, she does feel there are grounds for optimism as there is much more expertise now that there has been previously. At the same time, she is realistic about the current funding situation and the fact that good projects are not being developed as they might be. At the same time, autism is now not just the preserve of a few interested and knowledgeable professionals, but there is much more knowledge about autism and about the diversity of the autism spectrum.

Training and learning about autism

Clinical psychologists have a first degree in psychology, followed by relevant work experience and postgraduate training leading to qualification as a clinical psychologist. Currently, Sarah works in a CAMHS team and also works in schools.

Sarah gained her post-degree experience working in an organisation providing intensive behaviour interventions for children with autism. This involved Sarah in working in people's homes and getting a "real feel for what it's like to live with obviously what's quite a disabled child with autism." Sarah really enjoyed this work, and, in particular, working with the children and their families. Although she accepts that parents can be quite upset discovering their child has autism, she finds this difficult, as her experience of working with children with autism was so positive.

Sarah has a real interest in and passion for working with people with autism, but she recognises that knowledge and expertise varies amongst clinical psychologists, even though they tend to be regarded as the experts in autism in NHS mental health and children's services. It is probable that most will have only had about the equivalent of a day of formal training during their training course. (This is very similar to the experience of the medical student I spoke to who had had a placement in a neurological centre, but still had has very little formal training in autism.)

Interagency and intra-agency working

At present, Sarah works in CAMHS. CAMHS is a multi-disciplinary service and Sarah works with nurses, SLTs, dietician, psychiatrists, psychologists and psychotherapists. There is an emphasis on professionals working together co-operatively.

The core team dealing with autism consists of a clinical psychologist, psychiatrist and SLT. This team is not hierarchical in the sense of the psychiatrist leading it, but there is a recognition that "everybody is an expert in their own particular field". An example of this changing hierarchy is the diagnostic clinic, which is run by the SLT with the psychiatrist.

I asked Sarah about the relationship between the child development team (CDT) and CAMHS, given this can be confusing for parents and others. Children under 7 normally go to the CDT and over 7s to CAMHS, but if a younger child has been referred to CAMHS for a different reason and it becomes clear that there is a social communication difficulty, CAMHS would probably diagnose rather than referring to the CDT. There tends to be little of transfer of children from the CDT to CAMHS, but rather, once diagnosed, there is a tendency to discharge rather than offer continuity of care. The child might then be referred to CAMHS at a later stage due to the development of mental health issues, such as anxiety.

Sarah has found that a close involvement with a local NAS branch has been useful, especially when it has been possible to offer parents of newly diagnosed children the Early Bird course. However local NAS branches do not exist everywhere, and Sarah recognised that having an effective branch is dependant on "whether people have the time and energy." She would like to see more attention given to how "excellent local voluntary and not for profit agencies working with children" are supported.

When discussing children referred to CAMHS following transfer to secondary school, Sarah said: "I think we work in quite a bunkerish way. We don't work very well with other services. We tend to at that stage, to go, 'oh yea, yes they've got autism or whatever,' and we, we probably do a little bit of work with the school about what does autism mean, and then we rely on the educational psychologists. And my experience is that some educational psychologists are really brilliant at that, and some have not had very good training and are not particularly experienced in it."

At another point in the interview, I asked Sarah how good agencies were at working together. Sarah suggested that this was largely dependant on having some people who wanted to work together, and minimal anxiety about where funding was coming from: "In my experience, it depends on a few enthusiastic individuals making those links and then working up – and certainly my own experience of interagency working – there's a lot of suspicion about other agencies, their motivations, their funding, and a lot of that gets in the way of good cooperative work. I think that might be because money is particularly tight at the moment. I have seen better examples of interagency working in the past where it didn't seem quite so important about who was funding what. But now I'm finding it's a real struggle to – for people to say these people have the right to access our service."

2011 Green Paper

The Green Paper supports the view that interagency cooperation is needed, and propounds the idea of an education, health and social care plan. I asked Sarah her thoughts on this: "Well in an ideal world, if it gets properly funded, it would be brilliant – umm – I suppose my suspicion, and I know a lot of parents' suspicion is that it's just a way of making sure that there's less money for resources. Unless there's some real clout behind it, some real commitment to saying we're going to put together multi-agency teams that are really committed to these sorts of outcomes, then nothing's going to change much. In fact it might get a bit worse. So yes in theory, it's a great idea, and I'm sure the people that sort of came up with it were very committed to it as a principle, but it does need proper funding, and

some real planning to go in at the interagency level, if it's going to work at all. And I'm certainly not seeing that sort of work going on at the moment."

The Green Paper appears to recommend the establishment of a two-tier system, where those children who are most needy will be offered a single assessment process leading to an education, health and care plan, while other children will be helped through school level provisions. I asked Sarah what her thoughts were on this and she related this to the current system. "I think that's going to be really tough for school in the same way that it's quite an awful system for children. You know they have to multiply fail before they get to the stage of getting a statement, which I think is horrible. We'll put them on School Action and then School Action Plus and then they'll sit for quite a long time and there has to be a lot of evidence of them failing at that before they get what they actually need."

Parents

Once a child has been diagnosed, it is very often "left up to the parents to identify the support for their child." Sarah did not see this as a satisfactory situation, but would like to see both CAMHS and the CDT "being more involved in the ongoing care with children." Parents need more than just to be told their child has autism – they need to be told what that means and "what does that mean in terms of you being a parent and doing the best thing for your child." Rather than seeing diagnosis as an end and time to discharge a child, it should be seen as the beginning.

I asked Sarah what her thoughts were on the description of the SEN system as adversarial, as used in some recent government documents. She commented that she considered it was still adversarial, but suggested that at one time she had thought it was still more adversarial. It is possible that aspects of the service that lead to differences of view between parents and professionals are actually good practice. Sarah gave the example of a family where an EP had worked closely with a family from the time when the mother voiced concern, through suggesting a diagnostic assessment through to assessment, but the mother still found it very difficult to cope with the diagnosis. Sarah suggested that there is a problem in that parents are often overwhelmed by the information they are being given about their child's difference, and at the same time as they are trying to cope, they are being asked to make complicated decisions about the child's needs. She felt that "as professionals we focus on the child, whereas really we should be focusing on the family, getting the family through this."

Although it is important to parents to get a diagnosis, having a diagnosis does not necessarily give access to services and support. There is a real need to help parents to understand what the diagnosis means for their child, which may be very different to what the same diagnosis means for another child. "The diagnosis doesn't mean anything at all in terms of what they should or should not be entitled to."

Sarah challenged my assumption that it was more likely to be mothers that were involved with their child through the diagnostic process and suggested that for both parents there was a need to come to terms with who their child was and what they might achieve. She likened this to the process that all parents go through in having to temper their ambitions for their child as it becomes clear they are not "going to discover a cure for cancer and land on the moon and write a Nobel prize winning novel," but for parents of children with autism, that process is gone through often when the child is very young.

A particular problem for parents is they do not have the big picture. They probably have not encountered other children with autism, and have little knowledge of what the future might

hold. "That's something experts can help with because if you're a parent you're seeing it in the here and now and what you haven't seen is lots and lots of other children going through this process."

Deskilling parents

Parents benefit from being in touch with other parents. Sarah spoke of an online forum which she reads: "I listen to the parents there talk about these experiences. I feel incredibly guilty because there's something overwhelming about the number of professionals you meet that are experts. It's awful for the parents because in some way we make parents feel less expert than they are at being parents – and of course they are the absolute experts in their children. It doesn't matter what labels we stick on the children, they're the experts in that child as a person. But somehow the processes around diagnosis and SEN seem to really deskill parents." … "It's interesting a professional to think about what is it – how do we do that? - because it's not our intention. Our intention is to be supportive and to work alongside parents, but somehow that's not what comes across." … "I also work with children with learning disabilities… and you get the same sort of things. Just this huge crowd of professionals who all seem to be expert in your child, but actually, I think we need to put parents right at the centre of that because they are the real experts in their children and all we bring to it is a certain specialist knowledge of a little bit of their child."

Access to resources/rationing

Especially at a time when finances are limited, there is a need to ration resources. Sarah described the policy in her area as being very intensive interventions would not be offered "unless parents ask for it and fight for it, and, if they ask for it and fight for it, then they may well get it, but it's not offered as a matter of course." She went on to say: "You know, we're not even honest about saying, were only going to offer it for very disadvantaged children or children that meet this criteria. It's very much on a sort of whisper and tell." She put this in the context of being in an area which includes very affluent and very deprived families and pointed up the "real divide between parents who are prepared to fund interventions, fund legal interventions, get very well briefed, very well organised and fight that sort of SEN system and the parents that really just go with the flow and get what they are told." (This echoed some of what parents have said about information and about services which the authorities do not want parents to be aware of, and also what is said in some of the advice books written for parents.)

Sarah went on to say: "Money is tight and they like to ration it, and sometimes it's rationed by actually not giving out very much information and by putting parents through a very extended process that perhaps is unnecessary."

Another factor in accessing services can be having a professional acting as advocate for a child to receive a specific service. "if you've got a passionate professional who's prepared to be eloquent and argue and take on quite a lot of flak - it's quite surprising how much flak does come in for these people who are advocates for the people they work with. There's a lot of professional pressure and interagency pressure to just smooth things over and pour oil on troubled waters and persuade parents to settle for less than their children need. It can be very hard – and resources are tight."

On the other hand, "You do get parents who are arguing passionately for an intervention that genuinely the child wouldn't benefit all that much from. They would benefit quite happily from what they're being offered, but parents don't see it that way – so it's very hard."

Autism is unlike many other conditions because every child is different. With other conditions, it can be easier to categorise the child and to identify the services and resources that should be offered, but "for children with autism they're always individuals. They can be extremely able and extremely disabled at the same time, and enabling them to make the most of themselves but supporting the disability side of it can be incredibly complex."

Mental Health and Autism

A particular concern raised by Sarah was the poor service children receive when they have mental health issues. The mental health issues are often seen as part of the child's autism, "… and that's not true. You know, children with autism don't have to suffer with anxiety, they don't suffer with depression, they don't have to be disabled by overwhelming obsessions that are getting in the way of their enjoying themselves, and I wish more people would just think, ok they've got autism, but they've also got a mental health issue that somebody can do something about."

Anxiety, in particular, is very common. "Yes, it's really common – and just to be crippled with anxiety and not be able to access school at all – that doesn't have to happen. Children with autism don't have to have anxiety any more than any other child does. The reasons for their anxiety might be different, the way you cope with it might be different, but actually it is something that we can do something about."

Late diagnosis of high functioning children

"I've had a whole row of children where they've come in with all sorts of labels to come and see me either in school or in CAMHS…. I've sat with them for about 10 minutes and thinking what they need is a social communication assessment – how has anybody missed this, you know? And of course I work alongside whatever it is they've come in for, whether it's obsessions or depression or anxiety because they still need that work. It doesn't – giving them a label doesn't make that go away, but it's just so bizarre that it seems – I just struggle with why it's been missed, when to me it's really obvious that the underlying thing is that they just cannot work out other people and this is where this has come from, but it seems to be so easy to miss in higher functioning children."

Sarah was also aware that many children are referred for diagnosis following transfer to secondary school. "It's a really tricky time for children with autism. They move from a very nice predictable small primary school where they've known everybody and can predict how they're going to behave to this hugely unpredictable environment, and they tend not to cope very well, and people at that stage say, 'oh what do we do about this', and that's when they come to CAMHS."

In Sarah's view, the teenage years are difficult: "I think that's probably where it's at it's worst. You quite often find they have a bit of a dip and then they go on to really flourish as adults."

When the system breaks down

I asked Sarah specifically about here views on when the system breaks down, citing the example of a child who had been out of school for a considerable length of time because the school could not provide adequately for them, and there was a reluctance to offer alternative provision.

Sarah regarded this situation as unacceptable and "disgraceful", but went on to say that she worked with both good and bad schools. The problem seemed to arise when a child was not typical of children on the spectrum. The school might implement a TEACCH programme and provide a visual timetable, but if this failed to help a child, the school might struggle, leading to difficulties for the child. (This relates to the paediatrician's comments about a reaching assistant using ABA because it had worked with another autistic child, but in the particular instance, it was an unmitigated disaster.

I Sarah's locality, there is a very successful outreach service offered by a specialist autism school to other local schools, which has proved invaluable. "I think there needs to be something like the advisory service, working together with people like CAMHS and the educational psychologists." I asked what authority such a team should have and Sarah was clear that such a team needed to have "some sort of clout behind it and some sort of commitment at the top level of health, children's services and education. "As organisations in general, we're not brilliant at working together, and when it comes to this sort of more specialised ideas and ways of working together, then we're even worse."

Reflections

Many of the themes explored in this interview, mirrored or related to themes I have heard from parents and from other professionals. I could not help but be aware of Sarah's genuine interest in the work she does. When I asked if there was anything we had missed, she wanted to emphasise "what joyous work it is to do and how brilliant it is to work with children with autism and to help them sort out things. They're such an interesting bunch of people to work with and I think once you get that interest, it never goes away…. There's something completely joyous about being part of somebody's life in that way and putting your little bit of expertise into making their life better. I think if more people had that experience, we'd have a lot more experts in autism."

Alongside Sarah's passion for the work she does is realism. Money is tight. People are not getting the services they are entitled to. Rationing is sometimes achieved by withholding information. Agencies do not work well together, but protect their own territory. Parents are sometimes deskilled rather than supported and empowered.

There is far more expertise now than in the past, but the lack of finance combined with territorialism means that services are not always as effective as they might be. The Green Paper makes some recommendations that could make a real difference, but to achieve that requires attitudinal changes as well as changes in legislation.

I appreciated Sarah's candour and also the deep respect she clearly has for the young people she works with.

This was the first interview I have conducted using Skype rather than meeting face-to-face. Although there was the clear advantage of more effective use of time and other resources, the interview itself was far more structured than most of the other interviews have been. I am unsure whether this was simply the reality of speaking to a busy, professional at the end of a long day, the effect of the technology, or the stage of the research process where I am much clearer about the specifics of my research question and am wanting to home in on that area. I have another Skype interview planned and it will be useful to compare this aspect of the two interviews.

Appendix H

Themes emerging from literature and interviews

Themes from chapters 3 & 4	Practitioner Themes	Parent Themes
Access to information	Information Learning about autism Training	Information and understanding system Expertise
Partnership and Collaboration	Interagency perceptions, partnership and boundaries	
Stigma and marginalisation		Isolation and stigma
Diagnosis – contested and process	Diagnostic process Differential diagnosis SEN assessment	Diagnosis and comorbidity
Costs – financial and other		Costs and DLA
Policy development	Policy issues	
Availability of services / rationing / exclusion	Reorganisation / cuts / rationing / budgets	Exclusion from school or specific activities Accessing support
Social and medical models and inclusion	Inclusion – mainstream and specialist perspectives	Specialist placements
Fight / struggle / activist / advocate	Parental attitudes 'good' cooperative parent, parent 'in denial'	
	Personal guilt, regret and anxiety	
	Classroom management Behaviour management	Behaviour/difference and managing extreme behaviours
	Transitions	Transitions
		Private sector support
	System failure	Administration and maladministration
		Appeals