CHILDHOOD DISABILITY

IN BRIGHTON AND HOVE:

A GEOGRAPHIC PERSPECTIVE

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A thesis submitted in partial
fulfilment of the requirements of the
University of Brighton for the degree of
Master of Philosophy

March 2010

The University of Brighton

Abstract

This thesis presents an analysis of the micro-geographies of childhood disability in Brighton and Hove. Drawing upon a dataset of childhood disability (the Compass), which is administered and updated by a local voluntary organisation, and selected national datasets, quantitative research methods were used. The analyses exposed highly uneven patterns of childhood disability in Brighton and Hove. Childhood disability is generally tied to neighbourhoods with high levels of deprivation and disadvantage; the proportions of disabled children are several times higher in deprived areas in the east of Brighton than in less deprived areas of the city. It was found that disabled children living in the most deprived areas were more likely to have sole carers, live in housing their families considered inadequate and to experience multiple deprivation than those living elsewhere. High levels of bullying and school exclusion were noted for disabled children in Brighton and Hove; those living in the most deprived neighbourhood were at particularly high risk of school exclusion. Children living in more deprived areas were less likely attend holiday playschemes, receive short break services, or use Direct Payments compared to those with broadly similar levels of additional needs living elsewhere in the city.

These findings are compatible with the operation of the inverse care law and other kinds of social exclusion at a micro-geographic level. It is proposed that synergistic effects exist between area deprivation and disability at micro-geographic levels, compounding the risks of social exclusion for disabled children. This study serves to demonstrate the potential role of quantitative data and methods, and supports recent calls for geographic scholarship, particularly within the sub-discipline of Children's Geography. It is argued that this approach could provide a more robust evidence base for policy formulation for families with disabled children. It is asserted that by recognising that many disabled children live in pockets of deprivation within towns and cities of the UK, and that there are micro-geographic inequalities in the provision and receipt of services, policy makers and practitioners could more effectively mitigate the chronic disadvantage that appears to result from the intersection of childhood disability and area deprivation.

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Declaration

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I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed:

Dated:

Chapter 1

Introduction

1.1   Context of this study

A recent thrust of central government emphasises the need for local authorities to more effectively record and monitor the changing demographics of disabled child populations, and for research-based evidence which can inform public policies to reduce the social and economic inequalities experienced by disabled children and their families (HM Treasury, 2007).

The Disability Discrimination Act (DDA) 1995 defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. 'Long-term' means that the condition has lasted (or will last) for at least a year, and 'substantial' that it has a major effect. For children 'normal day-to-day activities' are age-dependent, so when determining whether a child is disabled it becomes crucial to assess whether they are able to perform everyday activites (like washing, dressing, communicating and getting around) as readily as other children of the same age.

There is a general consensus that understandings of the changing demographics and diverse local geographies of disabled children and their families are not well advanced in both academic and policy arenas (e.g. Imrie, 1996). Despite widely acknowledged legislative shifts in how and where disabled children are valued and positioned in society (e.g. Special Educational Needs and Disability Act (SENDA) (2001), DDA (1995), Education Acts (1981, 1993, 1996)), academics, researchers and policy makers continue to overlook how such new societal conditions are giving rise to different geographies of disabled child populations, and the ways in which disabled children 'experience the city' (Holt, 2004a).

This oversight is remarkable given the increasing magnitude and scale of disabled child populations in Great Britain over the last two decades (e.g. Abberley, 1991; Arthur and Zarb, 1995). Although there are no official fixed counts of the numbers of disabled children (Hutchison and Gordon, 2005), it is widely agreed that the frequency of childhood disability has increased in the last decade from approximately 3% to 7% (now 770,000 children) (Gordon *et al*., 2000; ONS, 2004). Disabled children are the fastest growing social group amongst the total population of disabled people (Prime Minister's Strategy Unit, 2005). At the same time, the spectrum of childhood disability is clearly changing, and becoming more diverse. For instance, there is an escalation in the proportion of children who are diagnosed with Autistic Spectrum Conditions (Medical Research Council, 2001), and the impacts of medical advances (i.e. the survival of increasingly pre-term babies) has led to higher proportions of disabled children with severe and complex needs (Jones *et al*., 2005).

The current gap in our understanding is exemplified at a broad level by the limited representations of the local geographic patterns of disabled child populations (e.g. McKendrick, 2001). Equally, the geographies of particular types of childhood disability, and the sociospatial linkages to particular types of neighbourhood and location, are unclear. There are few studies that shed light on the wider familial, household and social network patterns of disabled children and their families, and how such characteristics may change over time. Likewise, the ways in which particular neighbourhood characteristics (social, economic and cultural specifics of the residential neighbourhoods, availability of public services) may influence how disabled children are integrated and / or excluded from local communities, are under-researched. This lack of knowledge of the local geographies of the disabled child population will have significant implications for policy makers and service delivery professionals, and for the formulation of effective local and national policies to enhance the social inclusion of disabled children and young people.

Indeed, this perspective is pivotal to the recent Treasury Review of the spending on services for disabled children (HM Treasury, 2007: 29), which notes: "There is an inconsistent picture of data collection on disabled children at the local

level". As a result of this review, central government has now recognised that there is an urgent need for local authorities "to collect data on: the number of disabled children in their area, where possible classified by type of disability" (*ibid*). It can be argued that this approach needs to be more fully contextualised and extended by the secondary analyses of large-scale national datasets. A recent Economic and Social Research Council (ESRC) funded study (Alvanides and Woolley, 2007), aimed at understanding the unmet needs of families with severely disabled children, provides a rare exception, in that secondary analysis of a large dataset on families with disabled children is proposed. The intention is to collect data from 10,000 families with disabled children: this will measure the children's intrinsic levels of impairment and their levels of participation in activities that are considered part of everyday life for non-disabled children. By combining these findings with families' geographical locations, the aim is to uncover factors associated with high or low participation levels.

Underpinning the call for fuller understandings of the local geographies of disabled children is the alarming finding of a strong correlation between childhood disability and social exclusion (Every Disabled Child Matters [EDCM], 2007). This is exemplified by the following statements:

1. In 2000 the government made a historic pledge to end child poverty by 2020. When the Secretary of State for Work and Pensions announced progress for the first 5 years, he agreed that ending child poverty was a 'disability issue'.
2. By 2010 there are projected to be nearly 30,000 more disabled children living in poverty than in 2004/5 (Sharma, 2007).
3. There are 3 times as many families with disabled children in the lowest income quintile as in the top quintile (Department for Work and Pensions [DWP], 2004).
4. It costs on average over 3 times more to bring up a disabled child (Dobson and Middleton, 1998).
5. Families with disabled children are 50% more likely to be in debt (Emerson and Hatton, 2005).

6. Poverty increases the odds of low birth-weight by 61 per cent (Child Poverty Action Group [CPAG], 2005)

7. Only 16% of mothers with disabled children work compared to 61% of mothers with non-disabled children (Langerman and Worrall, 2005).

8. Only 38% of families with a sick or disabled child contain 2 working adults, compared with 55% of families generally (Carers UK, 2006).

9. The government has identified that as many as three-quarters of families with disabled children live in unsuitable housing (Prime Minister's Strategy Unit, 2005).

10. Parents from minority ethnic communities and lone parents are least likely to access services (Chamba *et al*., 1999).

11. Less than half of the total population of disabled children claim Disability Living Allowance (DLA), with the most disadvantaged the least likely to claim DLA (Preston and Robertson, 2006).

Clearly, deepening knowledge of the patterns and ways in which disabled children and their families experience social and economic disadvantage will inform broader discourses which seek to pin down why social mobility is declining (Dorling and Thomas, 2004), and why British society is becoming more polarised, reversing the trend of the hundred years prior to the 1970s (Dorling and Rees, 2003; Dorling *et al*., 2008). For, as Dorling *et al.* (2008: 36) state:

> "…if recent trends continue into the coming decades, although we may not notice the change year on year, like lobsters not noticing the heat turning up in the pan, Britons will come to live in an extremely segregated, fragmented and alienated society in the future".

1.2   Geographies of Disabled Children

It is surprising that knowledge of the geographies of families with disabled children is not well advanced, and continues to be overlooked by many local

authorities and voluntary sector organisations. For instance, the 1989 Children Act required all local authorities to keep a register of disabled children to monitor the quality of local services for disabled children and inform the planning of future services. Registers also have a related role to provide an information conduit through which families can receive information from, and give feedback to, the local authority on children's services and relevant issues. As registration is often voluntary, in many areas families choose not to register, so the databases often grossly under-represent local populations of disabled children. Opportunities are therefore missed for registers to become stronger tools in specific and general service improvement.

While many registers act as information conduits, relatively few registers, or, indeed, local authorities or primary care trusts, analyse the changing demographics and needs of this major cohort of disadvantaged children. This situation is perhaps unremarkable given the general dearth of studies analysing health and social inequalities at small area levels. However there is clear evidence that small area mapping is often both necessary to reveal health inequalities, and crucial in understanding local patterns and spatial processes (Foley *et al.*, 2005).

But, according to Her Majesty's Treasury (2007: 32):

> "A clearer picture of the disabled children population and disabled children's needs at a local level is essential for effective planning, commissioning and provision of services. The Review's fieldwork suggests that although some Local Authorities are developing a good understanding of their local population, and undertaking thorough needs assessments to help plan and predict the services and interventions disabled children and their families will need, others still do not have a proper understanding of the profile or even the size of their disabled children population".

1.3   Rationale for selection of the case study

To explore the 'hidden' geographies of childhood disability, Brighton and Hove was selected as a case study. This local authority is viewed by leading policy makers in the arena as a pioneering local authority that effectively records and understands the disabled child population (personal communication, C. Lenehan, Director of the Council for Disabled Children). Brighton and Hove was recently selected as one of the 21 Pathfinder local authorities for delivering short break services to disabled children (residential and other respite care and leisure activities), the first phase of the HM Treasury's new enhanced funding investment into services for disabled children. Importantly, Brighton and Hove's bid for Pathfinder status made explicit reference to a local database of childhood disability and families with disabled children   (the Compass), which is administered and updated by a voluntary sector organisation in the city (Amaze).

Viewed as an example of good practice within the national context (for example, by the Audit Commission (2003) in their review of services for disabled children, and by the Prime Minister's Strategy Unit (2005) in their report on improving the life chances of disabled people), the Compass database records information about local children and young people with disabilities and special needs, up to the age of 20. Registration is incentivised by issuing a Compass leisure card. Over 1,000 children and young people have current Compass registration (at mid-2008), meaning they have joined or updated their details in the last two years. Compass membership includes approximately 30 - 40% of the estimated disabled child population in the city (assuming 5 - 7% of children are disabled). There has been a four-fold growth in the number of registrations since the launch in June 2002. In light of the value that parents of disabled children attach to the Compass, the register has achieved much higher representation than almost all other such children's databases (such as InfoXchange covering Leicester, Leicestershire and Rutland   [http://www.infoxchange.org.uk],   Lancashire's   FIND   database [http://www.lancashire.gov.uk/corporate/web/?siteid=2951&pageid=5864],   and the   Sheffield   INDEX   [http://www.sheffieldchildrens.nhs.uk/services/2-2disabilityindex.php]).

To date, investigations of childhood disability using the Compass dataset have been limited to descriptive analyses, yet have informed the delivery of local services for disabled children and their families in significant ways, such as the need to proactively target the hardest to reach locations in Brighton and Hove. Without doubt, descriptive analyses have proved fruitful for identifying geographic differences between the disabled child population in Brighton and Hove. For example, children living just in the two wards of the city that were rated in the top 5% most deprived in the country (according to the Indices of Multiple Deprivation, 2000) account for 25% of all those on the Compass. Analyses focusing on leisure and childcare services and short break (respite care) services have suggested there are significant societal processes to be investigated about social inequality, deprivation and discrimination 'hidden' just below the surface in the dataset. (Amaze, 2005; Amaze, 2007).

To fully exploit the potential of the Compass more sophisticated statistical analyses of the data are clearly needed. For instance, interpretations of the analyses may be strengthened via a fuller contextualisation of the data by exploiting large-scale secondary national datasets, such as the GB Census of 2001, the Indices of Deprivation (2004 and 2007), the Controlled Access Microdata Sample (CAMS) records from the 2001 Census, and The ONS Longitudinal Study (LS) containing linked census and vital event data for one per cent of the population. Descriptive analyses of the Compass, for example, point to potential inequalities in the diagnosis of ASD and links to the uneven geographies of affluence and deprivation in Brighton and Hove. Utilising, manipulating and analysing the large-scale datasets of the GB census and LS to complement analyses of the Compass, could provide the impetus for investigations of new research questions which academics, researchers and policy makers have not been able to pursue due to lack of knowledge of and access to the data and appropriate experience and expertise of statistical skills (Holt, 2006).

This is particularly pertinent within the social sciences, since childhood studies and studies of the geographies of disability have tended to shun the use of quantitative data and methods, due to epistemological concerns (Philo, 2000;

Bushin, 2008). This project therefore aims to inform academic fields which focus on geographies of children and disability. These 'new' geographies have been tied to the 'cultural turn' in the social sciences (Philo, 1991, Cloke *et al.*, 2004; Scott, 2004; Johnston, 2006), and this has led to a dearth of studies utilising quantitative analysis of *secondary* large-scale data sources within these important research fields.

1.4 Aims

The aim of this thesis is to investigate the micro-geographies of childhood disability in Brighton and Hove. The research objectives are:

- To map and analyse the spatial distribution of children with disabilities in Brighton and Hove using the Compass and other secondary datasets.
- To consider how deprivation and different types of neighbourhood inter-connect with childhood disability.
- To investigate how place of residence impacts on the social exclusion of disabled children, using the examples of bullying and school exclusion and receipt of short break services.

As noted by Her Majesty's Treasury (2007), many local authorities lack basic information on the numbers and spatial distribution of disabled children. In Brighton and Hove, where the numbers of disabled children are unknown, the Compass provides a major, albeit incomplete, source of information about the local population of disabled children. Obtaining basic demographic information is one fundamental aspect of understanding more about childhood disability in Brighton and Hove. Therefore one major aim was to map the spatial distribution of children on the Compass. This information might also add an important dimension to the planning of effective services for disabled children locally. However, an inherent limitation of the Compass is that it is a voluntary registration dataset. Therefore it underestimates the numbers of disabled children and probably under-represents some cohorts of children (such as those living in certain areas, or of particular ages or with certain types of disability). Therefore, an important parallel aim was to identify secondary datasets that might provide

complementary information to the Compass (relating to childhood disability and health) and then use them in comparative analyses.

To understand how deprivation and different types of neighbourhood connect with childhood disability in Brighton and Hove, it is necessary to know how the levels of deprivation vary across the city. Therefore another early aim was to describe the demographic profile of the city, with particular emphasis on children and deprivation. The next aim was to analyse the Compass dataset to determine whether the life circumstances of disabled children living in more deprived areas and neighbourhoods were substantially different to those living in less deprived areas.

Another major research objective was to investigate whether place of residence impacted on the social exclusion of disabled children in Brighton and Hove. Although most people have a broad understanding of what is meant by the term social exclusion, it is an ill-defined term and it is usually applied to adults, often in the context of paid employment. Therefore the next aim was to consider what variables it might be appropriate to use to measure social exclusion of children and young people. The next aim was to assess whether disabled children living in deprived areas and neighbourhoods of Brighton and Hove were at greater risk of social exclusion, using a range of Compass variables that were highly relevant to the social exclusion of disabled children and young people, including exclusion from school and the receipt of leisure and short break services.

A final aim was to consider how the micro-geographic knowledge of the social disparities encountered by disabled children in Brighton and Hove might be more widely applied in national and local policy formulation, in local service planning and delivery, and to academic studies.

The remainder of this thesis is divided into eight chapters. In Chapter 2, literature on Children's Geographies and Disability Studies is reviewed. In the next chapter the methods and approaches used in this thesis are outlined. Chapter 4 summarises the findings from the Compass dataset on the uneven geographies of childhood disability within Brighton and Hove and considers whether secondary

datasets can complement or enhance this voluntary registration dataset. In Chapter 5, a demographic analysis of Brighton and Hove, focusing on children and young people, is presented. Extreme social polarisation of children and young people within the city was found, that would have been obscured by simplistic application of Super Output Area geographies. In Chapter 6, analyses of the rich Compass dataset revealed connections between disabled children's place of residence within Brighton and Hove and their experience of disadvantage, including multiple deprivation. The following chapter focused on school exclusion, a prime category of social exclusion in childhood, and high area deprivation was found to be strongly associated with both school exclusion and bullying of and by disabled children. In Chapter 8, families' receipt of short break services was explored, in the context of the severity of their children's needs, and area deprivation and neighbourhood were strongly implicated as barriers to their equitable receipt. In the final chapter the academic contributions of this work and potential approaches the work has suggested for improving practice in defining, and providing services for, local populations of disabled children are discussed.

Chapter 2

Literature Review

Introduction

Knowledge of the differential socio-spatial expressions of childhood disability can be enriched by a more critical geographic perspective. Based on this premise, this chapter outlines the rationale for the quantitative analysis of locally-captured information, provided by parents of disabled children and young people, which reports their children's additional needs, family lives and the services they need and receive. It is asserted that this approach will shed light on how, why and where families with disabled children are often socially and spatially marginalised. To date, understandings of why families with disabled children tend to be concentrated within particular types of neighbourhoods and are often socially excluded are limited in the sub-discipline of Children's Geographies. Equally, Critical Disability Studies of disabled children are lacking; thereby overlooking the patterns of inequality and difference that are often experienced by disabled children and young people. It is asserted that this orthodoxy is tied to a general side-lining of quantitative methods and data within Children's Geographies and Disability Studies *per se*; underpinned by an epistemological position which privileges qualitative data and methods (Holt, 2006; Bushin, 2008). This chapter is divided into seven sections. Section 1 introduces the development of the discipline of Children's Geographies. In the following section the marginalisation of disabled people, including the role of the medical model, is described. Next the development of the social model of disability and the discipline of Disability Studies is explored and in the following section the extent to which disability is socially constructed is considered. Next the discipline of Geographies of Care is introduced and finally the impact of environmental factors on health and disability are considered.

2.1   Children's Geographies

There is a consensus that Children's Geographies is a rapidly expanding sub-discipline (Horton and Kraftl, 2006; Matthews, 2003; Matthews and Limb, 1999; Tucker, 2003). Understanding how adults' views of children have evolved and changed over different historical times and how contemporary childhood is viewed in different parts of the world, provides useful background to understanding children's lives and experiences (Katz, 2004; Matthews, 2003; Qvortrup *et al.*, 1994).

In a seminal book, Holloway and Valentine (2000) summarise the timeline of the changing views and social constructions of 'childhood' (mainly in the Northern Hemisphere), culminating in the contemporary picture of childhood. In the Northern Hemisphere, in mediaeval times and the middle ages children and young people were viewed as miniature adults and it was only as late as the 16th century that children were beginning to be thought of as distinct types of beings, when (in wealthy families) they became the playthings of adults. During the Age of Enlightenment adults further elaborated on children's inherent difference (to adults). They viewed children either as little devils (naturally unruly, naughty and unsocialised) or as little angels. From the 17th to 19th centuries, Christian families strictly disciplined their children in order to defeat the devil within. In periods of high infant mortality this was considered important in preparing children for their eternal salvation. By the mid 18th century Apollonian views of childhood had emerged and children's natural virtues and talents were celebrated. The Dionysian and Apollonian views of childhood persist in Western culture.

Children in the Northern Hemisphere are now largely dependent on adults, not generally expected to contribute to the family's income (except for the minority of young carers), and over-consume a range of products. In contrast, in the Southern Hemisphere, where children account for a much higher proportion of the population, many do labour-intensive work that may be crucial for the household's survival.

As the characteristics and qualities presumed to be natural in children differ in time and space, we should view the category of 'child' and the notion of 'childhood' as social constructions (Aitken, 2000). What is more, whilst childhood is a different state to adulthood, it is something that all adults have experienced, so there is an additional complexity to understanding children as "adults' other" and "adults' becomings" (Aitken, 2001).

Having thus set the scene, Holloway and Valentine (2000) attempt to explain the current scope and aims of studies encompassed by Children's Geographies. Contemporary social studies of childhood are involved with analysing the social construction of childhood. These studies recognise that children are social actors, rather than passive subjects of social practices and processes. However, children's geographers also recognise that children's lives are shaped by additional factors beyond their control (Porter *et al.,* 2003). Globalisation, as well as localised effects, can affect the lives of children in both the Northern and South Hemispheres (Ansell, 2005). This is exemplified by the failing public school system in North America, because changes in the global economy have forced cuts in public spending (Katz, 1998). And the traditional farming practices children are learning in many rural places in the Southern Hemisphere are becoming redundant because global shifts are radically affecting the local agriculture (Katz, 1993). What is more, cultural factors such as class, race and gender, represent another layer of factors that shape children's lives and different identities (Valentine, 2000).

The geographical approaches to the new social studies of childhood began in the 1970s and 1980s, and gathered momentum during the 1990s (for example see Ward, 1978; Hart, 1979; Hill and Michelson, 1981; Matthews, 1984; Valentine, 1997; Aitken and Herman, 1997; Massey, 1998; Holloway and Valentine, 2000). Bunge (1971, 1977) focused on the urban life spaces of poor (African American) children, and found that their right to inhabit the city was tenuous: its landscape included rat bites, broken glass, empty lots and hit-and-run drivers. Bunge found that the urban (mainly African American) teenagers felt the full hostility of adult American society and were likely to be viewed as 'dangerous thieves' whilst the (white) college kids in the same city were labelled merely as 'pranksters'. Thus,

experiences of childhood were not uniform across space; they were deeply raced and classed. In short, childhood was a social rather than a biological phenomenon.

Importantly, Bunge's work was perhaps the most original example of the new 'radical geography', and this had major implications for the formation of children's geography. For instance, radical geography was inspired by the disjuncture between academic geography and real world socio-economic problems. It was conceived as a 'people's geography', a kind of geographical activism, in which geographers would study crucial social, economic and environmental problems, and would engage with the people experiencing the problems, with the aim of finding solutions. Blaut and Stea (1971, 1974) established a research agenda on children's geographical learning, including the acquisition of mapping skills, and they found that their spatial cognition developed much earlier and more acutely than models of child development had previously assumed, thus underscoring the importance of place and space to children.

These studies marked the end of a long period in human geography where the agency of children and their impact on families and societies tended to be overlooked. However, the pace of transition was slow enough for James (1990) to still be able to pose the question: 'Is there a place for children in geography?'

Similarly, Del Casino (2009) describes how geographers working on children were still marginalised in the 1980s and 1990s. Del Casino (2009: 190) recalls the leading children's geographer Cindi Katz remarking of her 1991 paper in the Annals of the Association of American Geographers (Katz, 1991): "I didn't want the word 'children' in the title because I wanted people to read it".

Geographers are increasingly concerned with exploring how childhood is understood differently across space (see for instance Holt and Holloway, 2006; Aitken *et al.*, 2007). Katz's work (Katz, 2001, 2002; Katz and Monk, 2003) has been pivotal in this move to deconstruct dominant notions of childhood emerging from the 'Minority World' of the Global North (Punch, 2002). In the Majority

World (the Global South), far from being dependents, children are expected to contribute to the family economy (*ibid*.). Katz (1991) examines the impact of globalisation on the lives of children in the poor rural village of Howa in central Sudan. Implementation of new forms of agriculture were intended to increase tenants' productivity and decrease the amount of time children spent labouring in the fields, enabling them to spend more time in school. But increased cultivation of cash crops meant that children had to forage further for wood and berries and grazing land and that they also became involved in working in the cash economy. Overall, therefore, they spent little extra time in school. Moreover, they were learning less from their families and their own life experiences about traditional rural agriculture (a way of life that was anyway being erased), but the new knowledge they acquired through schooling was not equipping them for their future (adult) survival in Howa. In her later work, Katz (1998, 2004) provides a counter-topography of young people in New York to explore how global processes impact upon both locations with similar, detrimental, outcomes on poorer young people.

In line with the increasing interest in the spatial, along with the historical, specificity of childhood, geographers are increasing keen to explore the social differentiations of children's lives (Matthews, 2003). Few authors have explored the issue of children's disability, however (although for exception see Holt, 2003, 2004a, 2004b, 2006). Indeed, Holloway and Valentine's (2000) landmark text on Children's Geographies does not consider disabled children or discuss disability as a life-shaping experience for children. This omission is all the more remarkable since disabled children are the fastest growing group of disabled people (amongst children, working age adults, and older people) in the UK (Pillai *et al*., 2007).

Interest in both the socio-spatial construction of childhood and the acknowledgement of children as agents are central components of the new geographies and social studies of childhood (James and Prout, 1990). Investigating children's lives required new methodological approaches. Matthews and Limb (1999) proposed a methodological agenda for studying children, the key points of which were:

- Children and Childhood are social constructions, based on adult assumptions of what it means to be a child and what environments children need, without realising that children have different ways of seeing to adults.

- Children's use of land and facilities differs from adults, and collisions resulting from children and adults using the same space in different ways are inevitable.

- Children are more restricted than adults in the spaces available to them. The constraints on their behaviour mean that, in some ways, they have more in common with outsider groups, such as disabled people and elderly people.

- Many childhood hazards are not (so) dangerous in later life.

- Children and adults may differ in how they see, feel and react to a landscape and in their views on environmental planning.

- Children have little control over the environments of greatest significance to them.

- Involving children in the design and management of their environment is important to their development as competent participating citizens.

Thus, the current emphasis is largely on the direct engagement or observation of children, with the objectives of understanding more about how they value their life experiences and the geographically relevant ways in which they differ from adults (for example, see Horton and Kraftl, 2006). This had led to a methodological orthodoxy prioritising qualitative methods and analysis as tools for researching children's geographies (Holt, 2006; Bushin, 2008), which this thesis begins to address.

The relative lack of quantitative analyses of children's lives and experiences is compounded by the limited interest in children within sub-disciplines that are dominated by quantitative approaches, such as population geography. In contrast to children's geographies, where children and childhood are the main subjects, McKendrick (2001) notes that in contemporary population geography children are often treated as objects rather than the subjects of the research. According to

McKendrick, children usually feature tangentially in studies on migration, mortality and fertility. For example, infant mortality is often measured but it is then used as an indicator of the general health of a population or, in longitudinal studies, as a marker of economic development. Family migration is extensively analysed, but the impact of children on migration is rarely considered. This is remarkable since children's ages and what stage in childhood they are at (and hence their perceived needs) are often crucial factors in determining family migration (Boyle *et al*., 1998; Bushin, 2009). Fertility concerns the addition of new children to the population. Children are effectively dehumanised in economistic models of fertility (which state that parents balance the number of children they have in terms of economic costs and returns). Even within socio-population geographies, children are generally studied as passive recipients of services (such as education, childcare or leisure). In response to McKendrick (2001), population geographers have begun to explore the lives and experiences of children (see for instance Bushin, 2008, 2009).

In contrast to Holloway and Valentine (2000), McKendrick (2001) recognises disability as one of the factors (along with age, class, gender, ethnicity) that fragments the child population. If children's geographers are to give full rein to their subjects, then it is important that they acknowledge that disability is one of the factors impacting on the lives of many children, be this directly, or indirectly (for example, because they have disabled siblings, parents or classmates; see Stables and Smith, 1999). Only then can they develop new methodologies and approaches that will be necessary to give disabled children an authoritative voice. For example, to ascertain the views of disabled children who do not primarily use speech, specialised and time-intensive augmentative methods of communication have to be used. However, assisting and augmenting the commoner communication methods is not, in itself, sufficient to empower all children to express their views. Many disabled children, particularly those who do not primarily use speech and those with cognitive impairments, often have few opportunities for making even very simple choices and decisions in their everyday lives (Amaze, 2006). So there are considerable challenges around enabling them to express their views, which go far beyond finding technical solutions. The process of Person-Centred Planning has been developed, and is

becoming more widely used, to elicit the views of disabled children and adults (Robertson *et al.*, 2005). This is a multi-session process, managed by highly trained, and specialist facilitators, that is designed to enable the disabled person to consider and communicate their views. It is however important to recognise that there are potential barriers to Person-Centred Planning, particularly in relation to availability of trained facilitators, availability of the service, lack of time and (in some cases) reluctance of people other than paid support staff to engage in the process (Robertson *et al.*, 2007).

2.2   The Marginalisation of Disabled People

Kitchin (1998) presented a thought-provoking overview of the multi-faceted nature of the marginalisation and exclusion of disabled people from mainstream society. Whilst agreeing with Oliver (1996) that disabled people are excluded because, under a capitalist regime, they are unproductive, he also argued that their marginalisation comes about because of attitudes, such as fear and stigma, not just capital relations. Importantly, he emphasised that space as well as time (history) impact on the segregation of disabled people, and that disablist practices result in and maintain spatial segregation (see also Imrie, 1996). Kitchin (1998) notes that geographers have hardly started getting to grips with examining the spatial processes that underlie disablism. It is argued that this may be because, despite insurmountable evidence of disabled people's marginalisation, which extends across the curriculum, the link between poverty and disability, is not often made or appreciated by geographers, or, indeed, by people in general.

In the case of disabled adults, marginalisation from mainstream society often includes exclusion from the workplace. Disabled people often also live in unsuitable housing and have restricted access to public transport. For disabled children marginalisation can take the form of segregated schooling and exclusion from mainstream play and childcare settings (Holt, 2004a, 2004b; Every Disabled Child Matters, 2006).

We do not have to look far along the shelves of any university library's collection of contemporary human geography textbooks, or delve far into contemporary government policy, to see evidence of disabled people being marginalised or excluded. In fact, it appears that their existence is frequently overlooked or, if it is acknowledged, their social differences and support needs are ignored or poorly appreciated. For example, Panelli (2004) explores why and how people are socially different and she analyses the power relations involved. Panelli's collection of essays begins with chapters on gender, race, ethnicity, and sexuality, but never mentions disability. Later on the author explores the relevance of identity, power, and social action. These factors are as relevant to an understanding of the social differences experienced by disabled people as by the groups that Panelli does consider. But by ignoring disability, the opportunity to think critically about the 'othering' of disabled people is lost; and the exclusion of disabled people is, by implication, sanctioned.

Gleeson (1999: 2) notes that geographers "sometimes seem reluctant to explore certain marginal domains of human experience". He argues that, the United Nations' recognition that, because of social and physical barriers, disabled people frequently live deplorable lives, leaves human geographers no excuse for being unaware of the marginalisation of disabled people. Although he acknowledges that some human geographers appreciate the dangers of researchers colonising, appropriating, and misconstruing the experiences of marginalised individuals and groups, he does not think this can fully explain their reluctance to research disability, since this is a fairly new debate within social sciences. Therefore, he discounts the possibility that geographers' reluctance was because they were wary of falling into the trap of speaking 'for' the disabled people they were researching, or of abusing the goal of conducting research that is emancipatory for disabled people (Stone and Priestley, 1996), and concluded that their silence largely reflected their exclusion of disabled people from the realms of authoritative knowledge. He contends that the failure of geographers to engage with disabled people has deprived them of a practical and conceptual resource that might have helped them in their struggles with professionals who have (often oppressively) shaped their environment. Along similar lines, Imrie (1996) argues that Geography is a spatial discourse of power that has underpinned the

development of disablism, most obviously in the creation of built environments that effectively exclude some disabled people.

The annual British Social Attitudes Survey reports current attitudes to a range of social issues. In 2008 it revealed that British people's attitudes to the poor were 'hardening', and they were less sympathetic to the unemployed than they had been (Park *et al*., 2008). British people also believed that there was still a long way to go before disabled people had equal opportunities to non-disabled people. We must assume therefore that, although the public appreciated that disabled people are discriminated against, most did not make the connection between unemployment and disability, and did not realise that many disabled people live in poverty.

Current Government policy sees getting people into paid employment as the most effective route out of poverty (Roulstone, 2002). But it fails to take account of the impact of the extra caring responsibilities that are imposed on parents of disabled children. Thus, government subsidises childcare costs to enable women to (return to) work, but basic childcare is generally not suitable for most disabled children, who have complex needs and/or challenging behaviour and/or are technologically dependent (Daycare Trust, 2008). In order to work, parents of children with such additional needs must be able to meet the additional expense of adequate and suitable childcare. Even if they can afford specialist childcare, they may ultimately be prevented from working because such services are in short supply. Hence this policy, which is apparently aimed at supporting *all* parents into work, discriminates against parents of disabled children, who remain excluded from the workplace. Indirectly, it also discriminates against disabled children as they miss out on attending childcare settings.

2.3   The Development of the Social Model of Disability

Since the rise of scientific medicine in the eighteenth century, disability in industrialised countries has largely been understood in terms of health and

illness, and viewed as a problem of individuals. The individual or medical model of disability - focuses on disabled people's functional limitations. According to the World Health Organization [WHO] (1980: 28), the term disability commonly refers to: "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being".

According to the individual or medical model of disability, the problem of disability is therefore located within the affected individual. It is the role of medicine and related professions to restore people who are disabled by their impairments to 'normality'.

These assumptions began to be questioned in the latter part of the twentieth century, with the politicisation of disability by disabled people in America, Britain and elsewhere. The individual model of disability, together with the 'invisibility', exclusion and marginalisation of disabled people, are the intertwined starting points for understanding more about disability activisim and the disability rights movement. In fact, recognising that the lived experience of disability is often one of discrimination is central to understanding the emergence of both the disabled people's movement in the UK and the social model of disability (Shakespeare, 1996; Crow, 1996).

Campbell (1996), a disability activist, reflecting on the history of the disability movement, notes that it only began to emerge in the late 1960s, when various other civil rights organisations (focusing on gender, race, and the rights of army veterans, for example) were already established. But Campbell considers it is too simplistic to conclude that these earlier movements directly spawned a disability rights movement. Campbell notes that very few disabled people had access to the ideas and arguments being made by these other groups, but that each of the mainly impairment-specific groups of disabled people had their own history of persecution and discrimination. Campbell saw the 1960s and 70s as the time when different groups of disabled people, who were beginning to question the charities and professions that had dictated the pattern and direction of their lives,

starting to speak out separately from them, and, in so doing, recognised that the broader issues they faced were also shared with other groups of disabled people.

In the UK in the 1960s a series of struggles by physically disabled residents for greater control over their everyday lives occurred in the Le Court Cheshire Home. The residents were subjected to an authoritarian regime by a management charged with their welfare. The long tradition and social acceptance of the 'cure' or 'care' roles of medical and welfare professions ultimately resulted in disabled people being treated as a commodity.

A flavour of the regime then prevailing at Le Court is apparent in Paul Hunt's description of the changes the residents were seeking (Hunt, 1981: 38):

> "…to extend the range of control over (their) lives …to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc".

Astonishingly, by today's standards, Le Court's management responded by blocking these requests.

Finkelstein (1991) provides an enlightened account of events. At that time, there was a long tradition of institutionalising disabled people, and residential homes were accepted as a legitimate means of caring for them. The managers of Le Court and similar residential homes were respectable, successful, able-bodied, people who assumed that the inability of disabled people to cope in mainstream society was due to their individual limitations. It followed therefore that they viewed the institutionalisation of disabled people as an act of kindness and so they would have been affronted by the residents' protests.

The residents next step was to seek 'evidence' to support their case for greater control by inviting two social scientists from the Tavistock Institute, who were experts in group dynamics, to research how the home was run. Miller and Gwynne visited Le Court and other residential homes for disabled people, but

their conclusions at the end of their long (three year) study appalled the Le Court residents. The researchers had interpreted their findings based upon the, then common, premise that once society committed disabled people to institutions they were 'socially dead'. Based on their preconceptions of disabled people, Miller and Gwynne (1972) concluded that the task of the management was to help inmates make the transition, as effectively as possible, from 'social death' to actual death. They found that residential homes fell into two types – ones with harsh regimes and ones with humane regimes. So they recommended staff training (a reworking of traditional practice) so that care would be humane. The residents considered that the researchers were parasitic and had followed their own agenda. However, Miller and Gwynne's notion of the 'social death' of disabled people helped crystallise the residents' view that the persistence of residential homes for 'the disabled' was a powerful reflection of the public's attitude and that they needed to find new arguments to end the tradition of segregation (incarceration) and break into society.

It was these events and lines of thinking that were largely instrumental in prompting the formation in 1975 of the Union of Physically Impaired Against Segregation (UPIAS). UPIAS, whose members all had physical or sensory impairments, was not interested in descriptions of how awful it was to be disabled, but in finding ways of improving conditions for disabled people. Crucially, in 1976 UPIAS redefined disability as:

> "the disadvantage or restriction of activity caused by a
> contemporary social organisation which takes no or little account
> of people who have physical impairments and thus excludes them
> from participation in the mainstream of social activities". (UPIAS,
> 1976, cited in Oliver, 1990:11)

In short, UPIAS was arguing that disabled people's problems stemmed from external, societal, factors rather than their medical problems. This ran counter to society's main solutions to disability, which, until then, had been those offered by the medical profession (and professions derived from it) of rehabilitation, cure, institutionalisation or even death.

UPIAS developed their argument further by saying that the elimination of disability required not only that disabled people take control of their lives but also that professionals must be committed to promoting that control (in contrast, for example, to the parasitic social scientists from the Tavistock Institute). They also stressed that the issues they faced (such as employment, income and mobility) should be addressed holistically, rather than as single and independent variables.

Campbell (1996) considers that by switching the focus from the individual's limitations to society's disabling cultures, UPIAS was instrumental in politically empowering disabled people (see also Morris, 1997). For many disabled people this was the first time that anyone had said to them that their disability wasn't their fault and, rather, that society was to blame. Thus, the development of social models of disability are intertwined with the emergence of the disability movement (Oliver, 1996).

Shakespeare and Watson (1998) judge the social model of disability to be 'the big idea' of the British Disability Movement. They point out that by arguing that disability was a form of social oppression, imposed on people with impairments, this enabled UPIAS to present a political strategy – barrier removal – as an alternative to the medical approach of 'cure' or, if that failed, 'care'. Now that disabled people were hearing an empowering message – society was the problem, not them – they need no longer rely on charity and goodwill. Instead they could demand their rights (see also Kitchin and Wilton, 2003).

Arguably, much of the power of the social model of disability was in its simplicity, as it enabled those within the movement to campaign for their rights under the powerful slogan: 'disabled by society not our bodies'. Paul Hunt, one of the Cheshire home residents, wrote to the Guardian in 1972 raising awareness of how severely disabled people living in such homes were effectively being abused. He described the authoritarian treatment and regimes and how their views were ignored. Paul Hunt's bold letter, written from his position of extreme marginalisation, also raised the political aspirations of disabled people.

In the UK, the disability movement has used social model principles to campaign for more comprehensive civil rights, anti-discrimination legislation and independent living. This has leveraged considerable social change. For example:

- Thousands of disabled people who lived in hospitals and nursing homes have been deinsititutionalised.
- Many public and government offices have been retrofitted to make them more physically accessible.
- Some urban spaces have been redesigned.
- Some television programmes are accompanied by signing or subtitling.
- There is a growing appreciation that many disabled people are marginalised from mainstream society.

Whilst the social model has been at the core of the UK disability movement, it is important to recognise that the ability to make collective protests, endemic to any people's movement, was also an important factor. In1996 members of DAN (Direct Action Network) staged a highly effective protest, choosing the time and place for maximum impact. They chained themselves to buses outside the House of Commons whilst Parliament was debating the proposed Disability Discrimination Act. In this way they highlighted the inaccessibility of public transport to wheelchair users and, in turn, the inadequacies of the proposed Act.

Campbell (2002) summarises the current climate as one in which the disability rights movement has been relatively effective against the medical interventionists and mighty charitable institutions, but in which it will have to continue to fight for full human rights for disabled people. The adoption of a social model approach in the amended Disability Discrimination Act (2004) highlights that a 'paradigm shift' (Oliver, 1996) in societal understandings of disability is perhaps taking place.

The social model of disability was devised by disabled people and describes how, on top of their impairments, they are disabled - restricted and limited - by the organisational, environmental and attitudinal barriers that exist within society (UPIAS, 1976). It was formulated in counterpoint to the individual model of

disability, which had been developed primarily by non-disabled people, from the medical and related professions, who were already authorised by society to cure or care for disabled people. They viewed 'normality' as 'able-bodiedness' and therefore saw disability as consequence of being a faulty or impaired individual. The impaired individual was therefore to blame, or was the problem. By locating the problem with the individual the implication is that they need to adjust to fit in (Brisenden, 1986; Barnes, 2003a).

Just as women's studies co-emerged with feminism, so disability studies co-emerged with the disability movement. The social model principles that were developed by UPIAS were given academic credence by Oliver, Barnes, Finkelstein and others. In 1992 Barnes coined the term 'Disability Studies'. Now universities around the world offer undergraduate courses in Disability Studies.

How did Disability Studies emerge? Meekosha (2004) sees it as an integral part of the development of the disabled people's movement – the intellectual arm of the struggle occurring 'within the academy against dominant and unreflective paradigms of normality'. The two founding fathers, Zola (US) and Oliver (UK), both had acquired physical impairments. But whereas Oliver, taking the Marxist view, ultimately saw the disability movement as part of a wider social struggle for equality, Zola was concerned with understanding why therapeutic relationships, particularly medical ones, cast people with impairments as inert (dehumanised). Thus one research tradition grew up in the social sciences and the other in the humanities. These different trajectories were determined by the cultural and political climate and traditions of the two countries.

The central criticisms leveled at 'mainstream' social science by disability theorists were that it discounted analyses of disability as a form of oppression, was disempowering and reinforced an individual (medical) model approach. Following the development of a social barriers model/approach to disability, academics began discussing the possibility of 'critical social research', with the emphasis on emancipatory goals and open partisan political commitment to them. The Joseph Rowntree Foundation (JRF) provided a forum for the development of the 'emancipatory research' paradigm by funding a series of

seminars, culminating in a conference, in 1992, on researching disability, that brought together disabled and non-disabled researchers and representatives of various research organisations in the disability field. According to Barnes (1992: 122):

> "Emancipatory research is about the systematic demystification of the structures and processes which create disability, and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment".

Emancipatory disability research promised an innovative approach to doing disability research. Disabled people and their organisations, rather than professional academics and researchers, would have control of the research process. By targeting not only the research process but also the funding agenda, the aim was to transform the material and social relations of research production. The core principles of emancipatory disability research, as formulated by the British Council of Disabled People (BCODP), are (reviewed by Barnes, 2003b):

Adherence to the social model of disability This was considered essential to reflect the growing demand by disabled people for a more holistic approach to the problems commonly associated with disability.

Giving control to disabled people Unlike conventional approaches, emancipatory disability research must fully involve disabled people from beginning to end. Non-disabled researchers could be involved but had to be accountable to a research advisory group or committee controlled and run by disabled people and their supporter organisations.

Accountability to the disabled community Research procedures and practices must be open and explained to research participants and participating organisations. The findings and implications of research must be disseminated in appropriate formats to all relevant audiences, especially to disabled people.

Empowerment of disabled people Emancipatory disability research should produce knowledge, understanding and information that has some meaningful

practical outcomes for disabled people in their struggles to overcome the barriers faced in disabling societies. It must attempt to leave disabled people in a better position to confront the disabling barriers in their lives and must not exploit their experiences for career benefits to researchers.

The role of experience Just as the social model is founded on disabled peoples' individual and collective experiences, it is important that discussions of disabled people's experiences are couched in an environmental and cultural context to highlight the disabling consequences of an increasingly ableist society.

The choice of methods These must adequately reflect the needs of the project concerned and the wishes of disabled people. Although emancipatory disability research has generally been associated with qualitative rather than quantitative data collection strategies, it is not the research strategies but the uses to which they are put that are important.

The growing critique of past disability research, by the disabled peoples' movement, may have been major impetus for the formulation of these principles. But also, at this point in time, there was a growing emphasis on market forces within universities and other research agencies. The wider policy context was also changing: service providers, and voluntary sector organisations were beginning to advocate a social model approach and government was backing measures to involve users in the planning and evaluation of services. As we reach the end of the first decade of this century, many more projects focusing exclusively on disability and related issues in the UK are now funded by charitable agencies and trusts (such as the Joseph Rowntree Foundation and the Big Lottery), that prioritise user-led initiatives and concerns over those of the academy and professional researchers. There is also a growing emphasis on user-participation, if not user-control, within academic research councils such as the ESRC.

However, since its inception, the extent to which the emancipatory research paradigm can be realised, and is sensible or necessary, has been the subject of ongoing debate. Most academics depend on securing long-term research

contracts for their future career prospects and continued employment, and they function within the professional and organisational constraints of the academy. So their capacity to follow the emancipatory research paradigm is limited. Indeed, it can even be argued that if research is located within the oppressive structures of the academy, however conducted, it is bound to keep reinforcing ableism (Oliver, 1992). On the other hand, organisations led by disabled people may have better credentials than academics for managing emancipatory disability research, but most are small and local and simply do not have the capacity or desire to accord high priority to funding for research (for example, see Kitchin, 2001).

The emancipatory research paradigm challenged researchers either to join with disabled people and use their expertise and skills in their struggles against oppression or continue to use them in ways which disabled people found oppressive (Oliver, 1992). Thus it risked criticism because it implied a "rampant subjectivity where one finds only what one is predisposed to look for" (Lather, 1991: 52).

There has been a long-running controversy over whether only disabled people could do disability research. Whilst Oliver (1992) argued that only disabled people could truly interpret and present data from other disabled people, Barnes (2009) has pointed out that having an impairment does not automatically give someone an inclination to do disability research or an affinity with people with similar conditions or disabled people generally. In fact, few disabled people have the time, inclination, skills or confidence to take over control of the research production. Kitchin (2000) interviewed 35 disabled people, the majority of whom worked in the disability field, about their views on emancipatory research. Most of them were aware that disability research was dominated by non-disabled researchers and that this created problems of representativeness. Some felt that, additionally, disabled people would be less likely to withold (the most difficult or embarrassing) information from disabled researchers and that the presentation of research findings by disabled researchers would have more of an impact. The vast majority favoured a partnership approach, where disabled people would have some degree of control over the research process and direction (although

some recognised that there was a danger in removing non-disabled researchers from the scene, as disabled researchers could also have their own agenda). The paradox, however, was that when offered the opportunity to research whatever aspect of disability they liked, almost all, except the few most politically active, declined. The main reason for not wanting to be actively involved was lack of time, but lack of confidence was also cited.

Concerns have also been expressed at the shortage of disabled researchers (Oliver and Barnes, 1997; Zarb, 1997). This is probably accentuated by disabled people's under-representation in higher education. Moreover, the infrastructure of academic research often does not accommodate individual support needs; this includes funding bodies not recognising that disability research often needs extra time and resources.

The commitment to user-control raises specific issues for research undertaken with people with learning difficulties. Kellet and Nind (2001) have pointed out that models do not exist for involving people with severe and profound learning disabilities as real partners in research, so these people are liable to be left out because they are perceived as too difficult to include. These authors justify their experimental research on people with severe learning disabilities on the grounds that even in experimental, rather than interpretative research, there is the potential power to do good, even to empower. They and others also note that findings from 'emancipatory' disability research could be used in unintended ways, perhaps to undermine disabled people's interests. For example, Mercer (2004) argues that user involvement in research has been exploited to provide 'intelligence' for service providers, enabling them to 'manage' rather than 'empower' disabled people.

Another concern was that disabled research participants did not always agree about their key interests: what benefitted one group, or individual, might be rejected by others. Indeed, the social model itself came under scrutiny for its preoccupation with the basic divide between disability and impairment. There were calls to widen the ontological gaze and include the experience of impairment (Morris, 1992). Otherwise research would only focus on the

structural bases of oppression. And not all disabled people found the social model (equally) inclusive; it was difficult or even impossible to conceive how this model, which separated impairment from disability, could work for people with learning difficulties and mental health difficulties.

Dewsbury *et al.* (2004) concur with Morris's concerns, and note that the social model has therefore failed to provide designers with useful insights into the social lives of disabled people. They argue that the social constructionist argument has replaced assumptions from one kind of professional - medical practitioners - with those of a different kind – sociologists; but as sociologists are concerned with the *form* of explanation, addressing *sociological* rather than *social* issues, in their professional accounts (2004: 152): "In these often impoverished theoretical accounts the everyday realities and activities associated with being disabled disappear".

Instead of searching for explanations, Dewsbury *et al.* prefer to take an ethnomethodological approach to understanding the everyday experiences of disabled people as this can inform design-related questions.

2.4   The Social Construction of Disability

Social constructionists are concerned with deconstructing positivist worldviews that see social facts, including social problems, as given and measurable entities. In other words: "social constructionists have an unrelenting concern with the blinding potential of the 'taken for granted'" (Dewsbury *et al.*, 2004: 149).

In the areas of health and disability studies, the kinds of questions social constructions ask are:
- Why did a condition get identified at a certain point in time?
- Why was action taken or not taken?
- Who benefits by identification, action and inaction?
- How do different perspectives on the phenomenon merge or clash?

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- How does the person's experience of the illness affect the course of the disease?
- What are the social outcomes of the illness?

Diagnosis is central to the work of all medical professionals, but it sets parameters for normality and abnormality and leverages social control (for example, in the past homosexuality was labelled as a mental illness). In some cases biomedical definitions and diagnoses are clear and uncontested. In other cases professional expansionism and/or the availability of drugs can medicalise normal functioning (for example, the availability of synthetic oestrogens prompted clinicians to medicalise the menopause as an oestrogen deficiency disease). On the other hand, medical and government authorities can be unwilling to legitimate some illnesses. Thus the scientific discovery of the AIDS virus and characterisation of the disease were delayed because of stigma, stereotypes, and judgmental attitudes toward gay men. Social activism was necessary before medical professionals would recognise that exposure to asbestos causes lung cancer. Sometimes labelling is sought by people to legitimate their condition, either to gain treatments or material benefits or social benefits (to their self-esteem).

Actions that follow from a diagnosis are also socially constructed. Medical staff may view some patients as more suitable than others for accelerated treatments. People who choose self-care options shape the future of their illness experience. People with some illnesses, such as sexually-transmitted diseases and epilepsy, may be preoccupied with concealing the illness to avoid being stigmatised. More broadly, political decisions also affect how services are allocated: for instance, despite overwhelming evidence that poor and minority children are most at risk of lead-poisoning they are still very under-served (Berney, 1993).

Viewed from the social constructionist stance, the apparent objectivity of the world is exposed as being constructed by a set of social practices. For example, Gergen (1999: 173) argues:

> "...many of the problematic narratives people bring into therapy are essentially the result of power relations in society more generally.
>
> ...if I believe I am depressed, and I must find a cure for my depression, I am essentially reflecting a story created by the mental health professions: I have swallowed the medical model in which I am the one who requires a cure for my deficiency".

The French philosopher, Foucault, also questioned social practices that had been regarded as natural, inevitable, and liberating. He focused on investigating the origins of our modern perceptions of disease and the body, the social production of madness, and technologies of normalisation. In particular, Foucault introduced the notion of biopower. He coined this term, which literally means power over bodies/life, to describe the increasingly comprehensive social management of individuals and populations based upon a knowledge of bodies. Biopower began to establish itself in the second half of the eighteenth century. Foucault emphasised that normalisation was at the core of biopower. Although, from our historical and cultural standpoint, it is perhaps difficult to believe, it was only in the middle of the 19th century that words like norm, normality, and normalcy appeared in the English language and the concept of "the norm" came into consciousness in Western societies. Davis (1997) explains that before this time the concept of "the ideal" dominated. However, the ideal was considered unattainable and ideal bodies therefore only occurred in art and mythology (for example, the nude Venuses in European art and characters like Helen of Troy in Greek mythology). Thus, in pre-industrial Europe, all members of society were below the ideal and there was no expectation that anyone could conform to it.

The concepts, and then the vocabulary, of norms and averages entered European languages largely as a result of the work of the work of the Belgian statistician, Adolphe Quetelet (1796-1874). Quetelet applied measurement and statistics to the natural history of health and disease and in this way he developed the notion of the average man. He equated this national 'average' with the middle classes and middle way of life that celebrated moderation, health living, and quietness:

"Deviations more or less great from the mean have constituted ugliness in the body as well as vice in morals and a state of sickness with regard to the constitution" (Quetelet, 1835: 289).

The machinery that ensued began by measuring birth and death rates, and, in time, almost every conceivable parameter of individuals and populations. The knowledge thus gained was used to control the population. As a result of biopower, human characteristics were medicalised, and medical, government and charitable institutions, and insurance, safety and surveillance practices came into being. Biopower was therefore responsible for the emergence of different and defined 'diseases' and different groups of 'disabled' people (such as deaf, mentally ill, insane, and physically-impaired people).

Foucault showed how the knowledge of human science disciplines (such as criminology, sociology, psychiatry, and psychology) that has emerged over the last two centuries was enmeshed with bio-power and the social management of individuals, and how, in its extreme form, although it emphasises the protection of life, biopower enables the state to identify and eradicate groups who are seen as a threat to the existence of the majority (reviewed by Tremain, 2005).

Foucault also noted that, through their classification, subjects come to know themselves and become attached to a personal and social identity. Hacking (1995) has expanded on this notion to explain how medical, psychiatric, and other human science classifications cause new 'kinds' to emerge into which people can be sorted. He has argued that when people are classified into particular kinds, knowledge of that classification has a looping effect, changing their self-perceptions. Importantly, the looping effect can, in turn, impact on the classification and change the knowledge about them. (In contrast, a similar grouping of non-human kinds lacks any looping effect, because the subjects are not 'knowing'.)

Some normalising technologies can be particularly insidious because subjects identify themselves and wish to be governed/normalised (modern day examples

include dieting and cosmetic surgery). These normalising technologies seem to offer choice but actually limit freedom and consolidate hegemonic structures.

From this backdrop it is easier to appreciate how and why some patterns of disease and disability have changed as nations have developed. For example, after the development of public health infrastructures (providing clean water and sewers, safe food, vaccines and so on), then nations undergo an epidemiological transition, from an era of (predominantly) infectious diseases to one of chronic diseases.

Of particular interest to this work, is the perceived increase in prevalence and variety of (neuro)developmental disorders. These include dyslexia, mild/moderate learning difficulties, Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Conditions (ASC) (also referred to as Autistic Spectrum Disorders [ASD]). Although the symptoms vary in their severity, children with ADHD usually find it difficult to control their behaviour, or to concentrate. ASCs are a group of lifelong developmental disabilities that affect the way a person communicates and relates to people around them. People with ASC experience difficulties with social interaction, social communication and imagination known as the 'triad of impairments'.

We would predict that new categories of disability will arise as a consequence of biopower extending its reach. As regulatory mechanisms are developed, so too is the ability to refine a disability's definition and to (sub)categorise people more and more precisely. For example, the recent escalation in the extent to which the academic achievement of schoolchildren is monitored, is likely to uncover ever more subtle categories of special educational needs and disability. Even within the apparently objective machinery of 'Public Health', there are political shifts in the expression of culture. Currently these include: increasing choice and personalisation of health services, a greater voice for users in planning services, increasing health surveillance and a greater tendency towards intervening in people's lives to promote healthier lifestyles.

2.5   Geographies of Care

In neo-liberal states there has been an increasing shift in health and welfare policies and practices away from state dependency models of care provision towards personal reliance and family support. In the last two decades UK policies on community care have shifted their focus from institutions to the home as the main site of care. There has been a concomitant erosion of public sector support for care in favour of a more diverse economy of care (Milligan, 2009). This shift has occurred at a time when disabled people have been largely de-institutionalised and (global) population ageing is accelerating.

Nearly 40 years ago Tudor Hart (1971) described the 'inverse care law'. He noted that people in deprived areas of Britain tended to have greater health needs but were less likely to access formal health care. The 2001 UK decennial census was the first one to ask people about their general health, any long-standing illnesses they had and about the time they spent providing unpaid care to others with physical or mental health needs (discussed by Wheeler *et al*., 2006). Shaw and Dorling (2004) examined the data on informal care giving, health status and occupation in the health services from this census. They found that the inverse care law still operated in England and Wales: medical care was provided inversely in proportion to need, with health professionals as a group achieving a south (eastern) bias despite the majority of their most needy client group living in the North. Importantly, they also found that informal care was provided in direct proportion to need: people in areas of higher need received disproportionately more informal care than professional medical care. Using a similar approach Kalogirou and Foley (2007) and Foley (2008) have analysed trends in the patterns of unpaid care giving at small area level in Ireland using information from the 2002 and 2006 Irish Censuses.

It has been argued that most community health and social care services would be unable to cope without the contribution of friends, family members and neighbours as informal, unpaid, carers (for example, see Arno *et al*., 1999, Bookman and Harrington, 2007, van den Berg *et al*., 2004). In 2008 the Department of Health estimated that 1 in 8 people in the UK were informal

carers, with up to 5 million of them caring for someone aged 65 or over (cited by Carers UK, 2009). In 2003 the national voluntary organisation, Crossroads, Britain's leading provider of support for carers and the people they care for, estimated informal care saved the government £57 billion per year (cited by Milligan, 2009).

Geographies of Care is concerned with exploring the relationships between people, place and care. The spatiality of care is interpreted largely as an ethical issue emerging from the increasing polarisation between rich and poor and intolerance to socio-economic, religious and cultural difference within society (Milligan *et al*., 2007). The range of topics covered includes:

- how care is manifest (who provides it, and how available/accessible it is) in a variety of different settings such as home, hospice, hospital, care home, and other community and voluntary settings.
- the notion of therapeutic landscapes (how people engage with the design of care settings, including, for example, whether they are in urban or rural settings and how informal or formal they are).
- the significance of designated sites of retreat as reparative and restorative environments for the self.
- the impact of the shift to home as the main site of care on older people and on care givers.
- the gendered nature of care.
- shifting power relations between lay people, professional care givers and care recipients.

Clearly, researchers working in the field of Geographies of Care engage with a variety of issues that arise directly from the shift towards more informal care. Perhaps of particular importance to families with disabled children, is the finding that this shift is placing an increasing burden on parents (in particular mothers) as care givers, yet by removing public provision for social support, their major role as informal carers is marginalised from view (Lawson, 2007).

Employment is a key government strategy for ending child poverty, but several factors make employment a difficult and unreliable route out of poverty for many parents (in particular mothers) of disabled children (Preston, 2005). The Childcare Act 2006 offered the promise of more childcare places and introduced specific duties for disabled children. Under Working Tax Credit rules, the affordability of childcare has enabled many parents to work. However the specialist childcare required by disabled children is often not readily available. Even if it is available (and fit for purpose) because Child Tax Credit ceilings are set too low, it is rarely an affordable option for parents of disabled children who wish to work (Every Disabled Child Matters, 2007). Thus, whilst some parents of disabled children actively make the choice to care for their child at home, for the vast majority of parents this is not a choice but a situation forced upon them by the lack of suitable childcare. This situation is compounded by the fact that it is still the norm for parents to have to take their children to attend medical and social care appointments, during the working day, at times that suit the professionals (Daycare Trust, 2007). Research around issues such as these could provide a rich vein of future research within Geographies of Care.

2.6   The role of environmental factors in health and disability

75 years ago paediatricians believed that the foetus was somehow magically protected from the environment by being in the womb. They thought that this protection was afforded by the placenta and by the foetal blood-brain barrier. The myth of placental protection was exploded when women in Europe started taking the drug, thalidomide, to combat morning sickness. A spate of births of children with flipper-like limbs followed because the drug had entered the placenta and, from there, had exerted its effects on the cells of the developing foetus (reviewed by Dally, 1998). The myth of any major protective effect of the foetal blood-brain barrier was exploded by the Minamata episode (reviewed by Harada, 2005). A plastics factory in the Japanese coastal town of Minamata was discharging metallic mercury into the coastal waters where it was converted (by sediment micro-organisms) to methyl mercury. This entered the food chain and

accumulated in fish, the staple diet of the local population. Babies with severe and complex neurodevelopmental conditions (including cerebral palsy, paralysis, and profound intellectual impairments) were born to mothers who had eaten the fish, yet the mothers themselves were almost entirely unaffected. Thus, the foetal brain was found to be highly vulnerable to (certain) toxins, which exerted their effects by crossing the foetal blood-brain barrier (Rodier, 1995).

The development of the brain is a complex and precisely choreographed/orchestrated process, involving massive numbers of cell divisions and cell movements. A strip of embryonic cells on the back of the foetus (where the spine will also form) divides many times and the cells migrate. Cells move along trajectories and normal development involves them interconnecting with other cells along their route. So if one or other 'partner' cells do not get to the right place at the right time, subsequent opportunities for developmental catch up are very unlikely (Rodier, 1995). Chemicals like methyl mercury, lead, and PCBs will disrupt this process. Depending on the precise dose and time the consequences may be subtle or they may be dramatic.

In the early years of the 20th century clinicians believed that the consequences of exposure of a child (or foetus) to a toxin was mechanistically similar to the consequences of exposure of people to a virus, such as the flu virus: either they would be affected or they would not. But by mid-century the myth of 'all or none' effects of exposure had been dispelled. A Boston hospital doctor, Randy Byers, who treated a boy who had tried to stab his teacher with a pair of scissors, noticed that 7 or 8 years earlier the same child had been treated for the convulsive effects of severe lead poisoning. Byers and Lord (1943) examined a cohort of 20 children who had 'recovered' from lead poisoning and they found that 19 of them now had violent or hyperactive behaviour.

In the 1990s a committee of the National Academy of Sciences reported that children were more susceptible to pesticides than adults (National Academy of Sciences, 1993). They found that, kilogram for kilogram of body weight, children have much greater exposure to environmental chemicals than adults because:

- they take in much more food, water, air, per kilogram of body weight than adults. In the first year of life an infant consumes seven-times as much water per kilogram of body weight as an adult.

- they are inherently more vulnerable – many enzymes that breakdown toxins in adults and therefore facilitate their excretion, are simply immature in children. (For example, the anti-cockroach chemical, chloropyrophosphate, has a half-life of 36 hours in babies compared to 4-6 hours in adults. It therefore has 6-8 times longer to cross the blood-brain barrier and cause neurological injury.)

- the foetus and young child are still developing. Development creates windows of unique vulnerability to environmental toxins.

- children have 6-7 more decades of life ahead of them, so they have much longer to develop symptoms.

The authors argued therefore that, with regard to environmental toxins, children needed particular consideration and protection in law. Until then pesticide regulation had assessed pesticide safety by 'assuming' that the whole US population at risk to exposure was made up of healthy 21 year olds.

2.7 Conclusions

The discipline of Children's Geographies has developed rapidly in the last few decades and its current focus is largely on investigating children's lives using direct engagement and observation. There have been relatively few quantitative studies concerning disabled children. This likely reflects the general exclusion of disabled people from society, including from the realms of authoritative knowledge. Children's geographers have rarely considered the strong link between childhood disability and poverty. Perhaps this is because children in relatively affluent families have been the subject of qualitative studies, and in disciplines, such as Population Geography, where quantitative approaches dominate, and it should therefore be easier to detect the link, children are rarely the subject of study and, if included, are usually only considered tangentially.

Following the development of the disability movement and the social barriers approach to understanding disability, the discipline of Disability Studies emerged. Until recently Disability Studies rarely included issues concerning intellectually disabled people, perhaps because of the complications intellectual impairment posed for the social model of disability. In other disciplines, including Children's Geographies, this group is under-represented but it may include some of the poorest disabled people.

Within Disability Studies the emancipatory research paradigm was formulated. Some proponents of the paradigm have questioned whether research performed by non-disabled workers, or done using quantitative approaches, can ever be truly emancipatory. However, geographical research on informal caring, which uses both qualitative and quantitative approaches, has highlighted the increasing burden placed on informal carers that has resulted from the shift in focus from institutions to home as the main site of care. An ethical geographies approach is being taken and the consequences of increasing social polarisation are also at the forefront of Geographies of Care. This kind of approach has contributed to highlighting the inequities carers in poorer families, including parents of disabled children, can experience. For example, for parents of disabled children, the barriers to parental employment, the government's preferred route out of poverty, can prove insurmountable. This is because the additional costs of specialist childcare and the need for flexible working arrangements, that are required to meet the additional care needs of a disabled child, are not adequately supported by government policies and benefits aimed at making employment an affordable option for parents.

Children's Geographies has largely ignored the role of environmental factors in health and disability, yet these often have distinct geographies and preferentially affect poorer people and people living in deprived areas. In the following chapters a quantitative study aimed at exploring the geographies of childhood disability in Brighton and Hove is presented.

Chapter 3

Methods

3.1 Choice of Research Methodology

This thesis has explicitly adopted a quantitative research design, in the light of the contentions outlined in Chapter 2 that Children's Geographies have overlooked the value of quantitative analyses/methods to understand the geographical variance of childhood disability. This thesis therefore builds upon Holt's (2006) and Bushin's (2008) calls for more quantitative research in Children's Geographies.

A Dictionary of Human Geography defines quantitative research methods as (Barnes, 2000: 663): "the use of mathematical techniques, theorems, and proofs in understanding geographical forms and relations". Qualitative methods are defined as (Smith, 2000: 660): "a set of tools developed to pursue the epistemological mandate of philosophies of meaning".

At this point in time, qualitative and quantitative methods are often represented as oppositional within geographies of children and disability (Valentine, 2006). But systematic knowledge and meaning are both important for understanding complex human worlds. So, if the aim is to develop a comprehensive understanding, quantitative and qualitative research methods should not be considered as mutually exclusive approaches.

It is important to deconstruct the apparent dualism between quantitative and qualitative methodologies (Flowerdew and Martin, 2005). This includes recognising that the processes that gave rise to the construction of the opposition between quantitative and qualitative methodologies were situated in particular historical and cultural contexts. The initial hegemony of quantitative methods, and concomitant construction of qualitative methods as non-scientific, were

cultural products. Later, feminist and post-structuralist epistemological critiques of the scientific method revealed the flaws of positivism, such as patriarchy, imperialism and social control. Thus qualitative methods were constructed as the tool of choice for non-positivist knowledge production.

The 'new' geographies have been tied to the 'cultural turn' in the social sciences (Cloke *et al.*, 2004), resulting in a dearth of studies utilising quantitative analysis of large-scale data sources. Since its inception emancipatory disability research has generally been associated with qualitative rather than quantitative data collection strategies. It is certainly true that large-scale surveys and detailed quantitative analyses can never fully capture the complexity of the every day experiences of disabled people. But the major objection was that such surveys were patriarchal and grounded in an ableist hegemony, and easily subject to political manipulation. For example, Abberley (1991) noted that the OPCS surveys on disability in the 1980s used a 10-point severity scale, which, on the face of it, would seem better than its previous 4-point scale. However, judging the severity of a problem is subjective and so this complex quantification served to imbue a spurious objectivity on the findings. Abberley (1991) also noted that the OPCS surveys, ostensibly aimed at determining the numbers of disabled people, really had at their heart state concerns, such as capacity to work and welfare benefits. The surveys saw disability as the individual's problem and investigated people's functional limitations without regard to the social and environmental context. Like disability studies, the discipline of children's geographies has also tended to shun the use of quantitative data and methods, due to epistemological concerns (Philo, 2000).

Quantitative methods are often thought of as complex and qualitative as simple. Hence, quantification implies precision and accuracy whereas qualitative research is associated with vagueness and lack of clarity. But some quantitative methods, such as descriptive statistics, are simple, whereas some qualitative methods, such as intricate theory development are complex. Thus simple studies can acquire scientific authority by virtue of being quantitative, whereas complex ones can be labelled as coffee table talk if they are qualitative.

In fact, some newer qualitative techniques, apparently concerned with representation and meaning, are based on systematic deduction and underlying patterns in texts. And qualitative techniques have routinely been used in the quantitative research (for example, the use of focus groups to develop structured surveys), but their importance has been downplayed. The call by Valentine (2006), to re-use qualitative data, acknowledged that researchers coming from different philosophical or theoretical positions may produce new interpretations or understandings of the data and also that this approach could contribute to identifying the impact of a researcher on the research process. Apparently rational quantitative techniques can be infused with the personalities and social commitments of the users and are place and time bound. In short, in reality, both types of study can be rigorous or sloppy, high or low quality, incisive or dull, depending on the task and the skill and objectivity of the researcher.

Denzin (1997) has challenged whether the qualitative, experiential, route, of 'giving voice' is, by itself, enough to bring about emancipatory change. He writes (1997: 54) of: "the belief that if lived experience is recovered, somehow something good will happen in the world".

Sheppard (2001) has argued that it is paradoxical to reproduce a qualitative – quantitative dualism, given that post-structural theory seeks to escape dualist thinking. What is more, it is a misrepresentation to claim that quantitative analysis must be positivist. Sheppard uses mathematical methods to critique neoclassical economic geography and uses GIS to better understand and improve the environments of marginalised communities. So he believes that progressive geography can take advantage of quantitative practices.

Fotheringham (2005:198) encapsulates the importance of data analysis in geographical research:

> "It can be used to make sense of large amounts of data, to explore data as a means of generating hypotheses and understanding spatial processes, to infer processes leading to the observed data whether those data constitute a sample or a population, to assess

the significance of findings, to help in model building, and in general to provide evidence for hypotheses about spatial processes".

As this thesis, unusually, in the current context of both children's geographies and critical disability studies, involves mainly quantitative analyses, it is useful to highlight what some of the potential advantages may be of using the quantitative approach in work on childhood disability in the UK at this time in history.

Whilst there are justifiable concerns about the use of large-scale surveys, because they reflect adultist and broader hierarchical social relations, engaging with these datasets presents opportunities for examining how 'other' childhoods, intersect with factors such as poverty, 'class', and geographic location (Holt, 2006). For example, quantitative analysis of secondary datasets has been instrumental in highlighting how child poverty varies by geographical location and it is likely that it could generate an important overview of the situation of groups of children, including (dis)abled children. The findings from such an analysis could, in turn, stimulate new avenues of in depth qualitative research on the lived experience of childhood disability, poverty and social exclusion.

A growing literature advocates 'mixed methods', where both qualitative and quantitative methods are used either simultaneously or at different times in the same project. However, identifying subjects, particularly if they are socially marginalised, who have the appropriate knowledge and experience, often poses a unique challenge for qualitative researchers. Studies involving quantitative analyses of a secondary datasets should define the cohorts from which individuals with the correct breadth of experience could be sought. Studies such as this one, involving quantitative analysis of relatively small primary datasets, could potentially even identify individuals within such cohorts who could be invited to contribute to ensuing in depth qualitative research projects.

It follows from this line of argument that collaborations between skilled qualitative and quantitative researchers could be particularly powerful. Similarly,

it is important for qualitative researchers to be able to read and interpret standard representations of quantitative data analyses (data tables, charts and graphs) and for quantitative researchers to appreciate the ways in which their discipline is socially constructed.

Holt (2006) has argued that if geographers engaged more with those designing large-scale surveys then greater contextual detail about children's lives could be sought. She notes that this approach led to same-sex couples being acknowledged for the first time in the 2001 Census. In 2006 a treasury review of services for disabled children was conducted because government recognised that these services had been under-resourced for many years. The first report on the evidence the cross party panel of MPs heard noted that pervasive themes running through the evidence included childhood poverty and lack of data on the numbers of disabled children in every local authority (House of commons, 2006). Although children's geographers can do useful work outside, as well as within, the arena of policy-relevant research, one specific policy-relevant role could be in co-developing a Census question that could better illuminate the nature of childhood disability.

Finally, it is important to note that quantitative language retains authority in (some) academic and policy worlds. So it may be strategically important to use quantitative methods when representing the interests of marginalised and disempowered groups. Indeed, Valentine's call to re-use qualitative data (Valentine, 2006) was made in part because policy makers were not interested in the findings from qualitative studies, but instead wanted 'hard evidence'.

3.2   The Compass Database

The Compass is Brighton and Hove's Database of Children with Special Needs, which is managed and co-ordinated by Amaze. Amaze is a voluntary organisation providing a one stop information and advice shop for families with disabled children in Brighton and Hove (www.amazebrighton.org.uk). Amaze

seeks to empower parents of disabled children and reduce the social and economic inequalities experienced by families with disabled children. Whilst its remit extends only to supporting local families with disabled children in Brighton and Hove, Amaze is active in the national as well as the local arenas. It is cited and commended by key policy makers and organisations, such as the Council for Disabled Children, as a leading and exemplary voluntary organisation in the wider national context of childhood disability. A key factor here is Amaze's delivery and co-ordination of the Compass dataset.

The 1989 Children Act imposed new duties on local authorities towards 'Children in Need', and recognised, for the first time, that disabled children should be included in this group (Her Majesty's Stationery Office, 1989). One requirement was that local authorities should keep registers of children with disabilities, that were intended to help them plan and monitor services for local families with disabled children, in the short and longer term, and to provide timely information on services to families. Local authorities were asked to find ways of enabling local health, social care, education and voluntary organisations to draw up a common register, the aim of which was to identify the number and needs of local children who had physical, sensory or mental disabilities or chronic illness. The act stipulated that registration was to be voluntary on the part of the parent or child and could not be a precondition of receiving services; but the potential benefits of registration - in terms of better service planning, the receipt of more timely information and opportunities for families to feed back their views on services – had to be explained. The Compass is Brighton and Hove's Children Act register and Amaze is the lead agency for this database.

Local children and young people can join the Compass if they have additional needs that significantly impact on their everyday life. They would typically be eligible to receive Disability Living Allowance or a statement of SEN. In order to join they should also be aged under 20, and live or go to school in Brighton and Hove, or be looked after by the city. Parents normally register their children's details, but can involve their children in the process, and young people over the age of fifteen can register their own details. Brighton and Hove's Children and Young People's Trust is the register's major funder and it is committed to using

anonymous data from the Compass to improve and develop its services for disabled children.

The Compass registration form is a four-sided questionnaire that was developed by Amaze in consultation with local parents of disabled children. Families can obtain Compass forms through the main local services disabled children use; Amaze can also post forms to families or they can be downloaded from the Amaze website. A copy of the registration form is included in Appendix 3.1.

The information families provide at Compass registration is entered and held in an Access database in accordance with the requirements of the 1998 Data Protection Act. Upon registration, children receive a Compass leisure card, which is valid for two years, offering free and discounted leisure opportunities. As a condition of Compass membership, every two years families update the information they provided at registration.

The Compass acts as a hub for sending out information to families on local issues, events and services and for families to feed back their views to Brightona nd Hove's Children and Young People's Trust. Based on the information families give to the Compass, the database team signposts them to relevant services and, from time to time, sends them targeted information on events, consultations and new services. If families raise serious or urgent issues they are referred to the Amaze telephone helpline. Families' collective feedback on services is provided to the city by analysing Compass data and reporting on the findings. If service providers want to send information to families (including invitations to consultations on services), the Compass database can be queried, to identify relevant families. As the Compass team (rather than the service provider) mails out the information, families' confidentiality is maintained.

In this thesis I elaborate on initial observations, made when the Compass had been running only for about three years, that the proportions of children on the Compass was much higher in some wards of the city than others. Most importantly, the over-represented wards contained areas that were considered to be amongst the most deprived in the city. Moreover, children on the Compass

living in the more deprived wards were, on average, more likely to be in single parent families, to have disabled parents/carers and to have disabled siblings, compared to those living elsewhere in the city. Much greater information could be gained about the disabled child population of Brighton and Hove by undertaking complementary and comparative analyses of large-scale national quantitative datasets, such as the Great Britain census, and Indices of Deprivation datasets. The exploitation of other national secondary data sets is often beyond the reach of workers in the local voluntary sector, but it can provide a fuller contextualisation and analysis of the local data such as Compass data. Similarly, few local voluntary organisations have the capacity for statistical analysis of datasets and these, applied to the Compass and/or secondary datasets, can also illuminate characteristics of the local population of disabled children.

By advancing Amaze's understanding of the local disabled child population, the evidence-base for informing both local and national policy makers should be more robust and hard-hitting. Moreover, building upon Amaze's national profile and track-record of forging examples of good-practice in the fields of childhood disability, this project could, in the longer term, lead to more robust analysis of large-scale national datasets by other local authorities and voluntary sector organisations charged with understanding their local populations of disabled people. This focus is integrated into the plan of the project.

3.3 The Indices of Deprivation

The English Indices of Deprivation 2007 (Noble *et al*., 2007) are the Government's latest official measure of multiple deprivation at small area level. The Indices of Deprivation (ID) are reported for every Lower layer Super Output Area (LSOA or SOA) in England every three or four years. This massive data collection, collation and reporting exercise provides some measures of the relative deprivation of SOAs within and between different local authorities and regions of England.

In his 1979 account of poverty in the United Kingdom, Townsend defined poverty in terms of relative deprivation:

> "Individuals, families and groups can be said to be in poverty if they lack the resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are customary, or at least widely encouraged or approved in the societies to which they belong" (Townsend, 1979: 31).

LSOAs have, on average, a population of 1,500 people. They are in most cases much smaller than wards, thus allowing the identification of small pockets of deprivation. There are 32,482 LSOAs in England. The majority of the ID 2007 data relates to 2005, though some is from the period 2003-2005 and some is derived from the 2001 Census.

In the ID 2007, the scores and ranks for 37 indicators of deprivation are recorded, across the domains of

- Income,
- Employment,
- Health and Disability,
- Education, Skills and Training,
- Barriers to Housing and Services,
- Living Environment and
- Crime.

Consultation and peer review supported weighting the individual domains in the following proportions to obtain an overall index of deprivation:

Income deprivation	22.5 %
Employment deprivation	22.5%
Health deprivation and disability	13.5%
Education, skills and training deprivation	13.5%
Barriers to housing and services	9.3%
Crime	9.3%
Living Environment deprivation	9.3%

This index is referred to as the Index of Multiple Deprivation (IMD).

As ID scores are allocated to each LSOA, the 32,482 LSOAs in England can be ranked for each domain, and for the IMD, so that relative deprivation can be determined:

- In the local authority,
- in other local authorities,
- in other regions, or
- in the rest of England.

The proportion of SOAs within a local authority which fall within the 10% (or 20%) most deprived nationally (the concentration of deprivation), or the proportion of England's most deprived SOAs that fall within each district (the extent of deprivation) can be measured. The ID 2007 indicators have been chosen because they capture different aspects of deprivation. However, it is important to note that a lack of deprivation does not necessarily equate to affluence. Therefore, the SOAs with the ranks closest to 32,482 are not necessarily the most affluent, just the least deprived, in England.

It is important to note that most of the domains have different scales and ranges of scores. So comparing an SOA's scores for different domains does not produce a meaningful measure of how similar in magnitude different types of deprivation are within it. Similarly, although an SOA's ranking, for different domains, or for the same domain over time, can be compared, it is important to recognise that its ranking will be affected by the ranking of every other SOA in England. Thus, a particular SOA could have increased in rank for a particular domain since the last ID exercise, without actually becoming any more deprived for that domain, because of decreases in the deprivation of other SOAs elsewhere in England.

However, unlike the other five domains, the scores for the Income and Employment domains actually record the proportion of the population within the SOA experiencing income or employment deprivation. Unfortunately, it is not possible to simply compare the ID 2007 and ID 2004 Income or Employment

deprivation rates in order to determine whether the population of a particular SOA has become more or less income or employment deprived since 2004. This is because there have been major changes to the way that the Income and Employment rates are reported since the last ID exercise.

It is also important to appreciate that a SOA's domain score describes the average situation for the whole SOA. So, within a SOA that is relatively deprived for one or more domains there may be some people who are not deprived, and within less deprived SOAs there may be some people who are deprived.

The IMD 2007 brings together the 37 different indicators from the seven domains, via an agreed domain weighting, to create an overall deprivation score and rank. However it is worth noting that the 'Index of Multiple Deprivation' does not directly identify the relative proportions of people experiencing multiple deprivation. Instead it records the relative proportions of each SOA's population experiencing a range of individual types of deprivation. It is an assumption that significant proportions of people living in areas with high ranks and scores for several domains actually experience multiple deprivation.

The impetus for the Indices of Deprivation exercise is summed up in the first sentence of the Preface to the English Indices of Deprivation, 2007: "Indices of Deprivation are an important tool for identifying the most disadvantaged areas in England so that resources could be appropriately targeted" (Noble et al., 2007: 3).

In short, the aim of this massive exercise is to enable service providers whose remit includes combating deprivation and social exclusion to plan where best to target their resources most effectively.

Whilst poverty results from not having enough financial resources to meet needs, deprivation reflects unmet need, caused by a lack of resources of all kinds, not just financial. However, low income remains a central component of multiple deprivation. As Townsend (1987: 131) noted:

"while people experiencing some forms of deprivation may not all have low income, people experiencing multiple or single but very severe forms of deprivation are in almost every instance likely to have very little income and little or no other resources".

The ID includes an income domain that records the proportion of people per SOA living in income deprivation. In 2004 and 2007 two supplementary indices to the income domain were included. They are:

- the Income Deprivation affecting Children Index (IDACI) , and
- the Income Deprivation Affecting Older People Index (IDAOPI).

The IDACI score is the proportion of children aged 0–15 living in income-deprived households (as a proportion of all children aged 0–15). Income-deprived households are defined as either households receiving Income Support / Job Seekers Allowance-Incapacity Benefit / Pension Credit or those not in receipt of these benefits but in receipt of Working Tax Credit / Chid Tax Credit, with an equivalised income below 60 per cent of the national median before housing costs.

The IDAOPI records the proportion of all those aged 60 or over living in Pension Credit (guarantee) households (as a proportion of all those aged 60 or over).

Whilst the IDACI and IDAOPI are *supplementary* indices, in the sense that they are separately reported, income deprivation affecting children and income deprivation affecting older people are also captured *within* the overall income deprivation index. In a SOA that has a high income deprivation domain score, it may be that the majority of people within the LSOA are similarly affected by income deprivation, or it may be that particular groups are more affected than others.

Therefore, to more effectively deliver services to children in need, it is important to identify small areas where there are high numbers of children living in income deprivation. It is important to recognise that the income domain of the ID, whilst

it would reveal relatively deprived areas, would not provide the best measure. First of all, in some small areas (made up of one or more SOAs) of some local authorities there may be strong overlap between the proportions of older people, children and young people, and other groups living in income deprivation. However in other small areas, there may be more restricted overlap between the proportions of these groups that live in income deprivation. Secondly, and again depending upon the unique characteristics of the district, there may be strong similarities or significant differences between the proportions of children and young people within the area's total population.

Therefore, if the focus of the study area is children in need, it is important to take into account:

- the proportion of children and young people living in income deprivation, rather than the overall proportion of people living in income deprivation,
- the numbers of children and young people rather than the total population.

In short, when planning the delivery of local services for disabled children and young people, it is important to consider the IDACI and the number of children and young people in each SOA in Brighton and Hove.

3.4   2001 GB Census

Census data for Brighton and Hove for several variables were extracted from 'Census Area Statistics on the Web' (CASWEB), a web interface to aggregate statistics from the GB Census, which is available online to the academic community via Manchester Information and Associated Services (MIMAS). There are advantages and disadvantages to the use of census data. Because of significant financial investment it tends to be collected in more robust ways than are available to thbe individual researcher (Rose and O'Reilly, 1998), but it has been collected by someone else, for another purpose (White, 2003) and this

government-generated information is potentially exposed to manipulation for political purposes (Hoggart *et al.*, 2002).

3.5   Databases used in this study

Several databases exist from which it might be possible to extract secondary datasets relevant to the study of childhood disability and poverty or deprivation in Brighton and Hove. The choice of secondary datasets used was determined largely by the limited (public) availability of relevant datasets at sub-local authority level. The main features and limitations of the datasets that were considered are summarised in Table 3.1. The limitations of the datasets used are discussed in more detail in Chapter 4, Section 4.3.

Table 3.1: Secondary datasets considered for use in this study

Name of dataset	Derived from	Highest resolution data is available	Limitations	Dataset used in this study
DLA claimants aged 0-15 years	All DLA claimants, published online at quarterly intervals by the DWP	LSOA	Numbers are rounded up/ down to the nearest 5 claimants at LSOA and ward level. DLA is only claimed by about 50% of disabled children; more disadvantaged families are less likely to claim (Preston and Robertson, 2006).	Yes
0-15 year olds with a limiting long-term illness (LLTI)	2001 GB Census table on people with LLTI	LSOA	For adults LLTI was self-assessed; for children LLTI was assessed by the householder.	Yes
0-15 year olds with 'not good' health (NGH)	2001 GB Census table on people who rated their recent health as 'not good'	LSOA	For adults 'not good' health was self-assessed; for children 'not good' health was assessed by the householder.	Yes
IDACI	A supplementary index included with ID 2007	LSOA	Percentage of 0-15 year olds living in income deprivation	Yes
Low Birthweight Births	Low Birthweight Births, published online via the NHS Clinical and Health Outcomes Knowledge Base	Local Authority	At local authority level data is available for babies weighing less than 2,500 grams, but (due to small numbers) is suppressed for those less than 1,500 grams.	No
Children with SEN (and children with Statements of SEN)	The National Pupil Database and the annual School's Census conducted by the DCSF	Local Education Authority	Some data are published at Local Education Authority level	No

Family Fund Database	Family Fund Database	Ward	Data is only collected about 'severely' disabled children in low income families who apply to the Family Fund for a grant. On request ward level data for Brighton and Hove was made available to Amaze.	No

3.6   Cluster Analysis

Cluster analysis is an exploratory, modelling, technique that seeks to identify the natural structures of groups based on a multivariate profile (Chan, 2005; Stockburger, 1998). It always generates clusters and the solutions are non-unique in that they depend upon the particular range of variables used and how cluster membership is defined. If one has little idea of the data structure, hierarchical approaches are used. Hierarchical approaches are either agglomerative or divisive. In agglomerative methods each object is placed into a cluster and new clusters are combined until eventually all items are grouped into one cluster, whereas divisive methods work in the opposite direction. In either case, the results of the clustering technique can be described using a dendogram. The objects are represented as nodes in the dendogram and the branches illustrate when the cluster method joins subgroups containing that object. The length of the branch indicates the distance between the subgroups when they are joined.

As cluster analysis attempts to measure similarity between items, variables with the greatest scale and variability will impact most on the results of the analysis, so, unless these parameters are thought to reflect the 'natural' pattern, it may be necessary to standardise the variables used. The algorithms used incorporate different distance measures, such as Euclidian distance (the geometric distance in multidimensional space) and City-block (Manhattan) distance, where the effect of single large differences (outliers) is dampened. They also incorporate different linkage rules for differentiating between clusters. For example, in nearest neighbour linkage the distance between two clusters is determined by the distance of the two closest objects in the different clusters, whereas in Ward's

method an analysis of variance approach is used to evaluate the distances between clusters.

Despite being something of an art as well as a science, cluster analysis has proved important in a number of fields, including:

- biological taxonomy - for illuminating relationships between and within species,

- marketing - for identifying and characterising different market segments, and

- geography - for classifying areas according to their environmental characteristics and/or the socio-economic circumstances of their inhabitants.

In this work cluster analysis was used to classify the populations in census areas within Brighton and Hove using a range of variables that contain information relevant to families with dependent children. Then it was determined whether each of the resultant clusters mapped to particular geographical areas.

Although cluster analysis is only an exploratory technique, if census areas making up particular clusters map to just one or a few contiguous regions, or to particular geographical features, this tends to suggest that the derived clusters reflect meaningful differences between the populations they describe. This general approach has been piloted by Shelton *et al.* (2006) as a method for deriving an area-based mortality profile for England and Wales and analysing changes over time. Ruger and Kim (2006) have similarly used cluster analysis to stratify countries into mortality groups (most healthy, least healthy, mid-level health) and found that those in the high adult mortality cluster all mapped in western and sub-Saharan Africa and Afghanistan.

3.7   Geographical Information Systems (GIS)

A GIS was used as both an analytical and presentational tool. The ESRI ArcView software was selected as it can be used to quickly and simply generate multiple

maps from data tables. Digitised boundary files for Brighton and Hove were obtained from the UKBorders website as ArcView shapefiles. In general a quartile classification scheme, in which each interval contains 25% of the observations, was used. Natural break and standard deviation approaches were trialled but, with many variables, large numbers of SOAs were classified in a single category, making the identification of spatial patterns problematic. The process of mapping the data was used integral to the analysis as well as to displaying the findings visually. Concerns have been raised within human geography about the links between GIS and strategic planning, commerce and the military and a deliberate ignorance of related ethical, economic and political issues (Pickles, 1995). Here GIS was used as one tool within a mixed methods approach and it thus provided a powerful way of communicating knowledge about places (Perkins, 2003).

3.8   Conclusions

This chapter has discussed the rationale for the selection of particular methods to address the main aims of the thesis. It is been argued that analyses of a range of quantitative data are essential for shedding light on the complex micro-geographies of childhood disability in the case study of Brighton and Hove.

Chapter 4

The Uneven Geographies of Childhood Disability
in Brighton and Hove

Introduction

The general absence of quantitative studies of childhood disability has led to a limited understanding of the micro-geographies of disabled children in the UK. Focussing on Brighton and Hove, this chapter commences with an analysis of the Compass dataset, to identify the spatial patterns of disabled children in Brighton and Hove. As a precursor, it is important to note that, since the Compass is a voluntary registration database, it does not include all disabled children in the city, so some will be excluded from this analysis. This point begs important questions about the potential of secondary datasets to provide local, small area, data relevant to childhood disability.

The chapter is split into five sections. As a preface to analyses presented later in the chapter, Section 4.1 describes super output areas (SOAs) and their relation to ward geography for Brighton and Hove. In the next section the numbers of disabled children included in the Compass dataset are mapped by ward and SOA in Brighton and Hove. In the third and fourth sections secondary datasets relevant to childhood disability are identified and their potential to provide small area data on childhood disability is assessed. In the last section the prospects for more accurately assessing the numbers and uneven geographies of disabled children within locales are critically discussed.

4.1 Super Output Areas (SOAs) of Brighton and Hove

SOAs, also known as Lower layer Super Output Areas (LSOAs) are a new type of geographical reporting unit. They are based on Census Output Areas and are designed to have roughly similar small population sizes. The average population of a SOA is 1,500. This means that they are well suited to the major purpose of the ID exercise, of identifying pockets of deprivation (Martin, 2002). There are 164 SOAs in Brighton and Hove and 32,482 in England. SOAs were designed to map within wards, so there is scope for longitudinal analysis with earlier data that was collected at ward level. SOAs (LSOAs) have also been aggregated to form Middle layer Super Output Areas (MSOAs), but MSOAs are not generally coincident with wards. There are 33 MSOAs in Brighton and Hove. A map showing the wards of Brighton and Hove is presented in Figure 4.1. In Figure 4.2 the ward, SOA and MSOA boundaries in Brighton and Hove are depicted.

1 Brunswick and Adelaide
2 Central Hove
3 East Brighton
4 Goldsmid
5 Hangleton and Knoll
6 Hanover and Elm Grove
7 Hollingbury and Stanmer
8 Moulsecoomb and Bevendean
9 North Portslade
Ward name
10 Patcham
11 Preston Park
12 Queens Park
13 Regency
14 Rottingdean Coastal
15 St Peters and North Laine
16 South Portslade
17 Stanford
18 Westbourne
19 Wish
20 Withdean
21 Woodingdean

Figure 4.1: Ward map of Brighton and Hove

60

(a) Wards
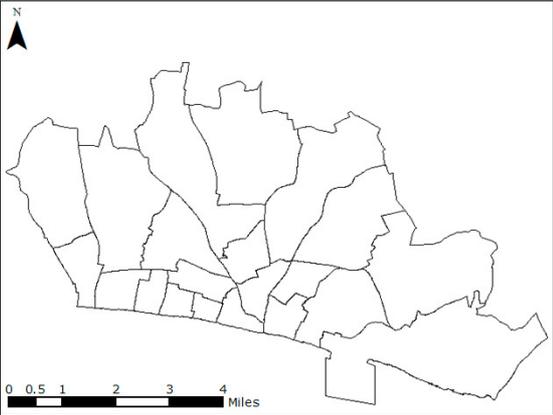
(b) Lower Layer Super Output Areas (LSOAs)
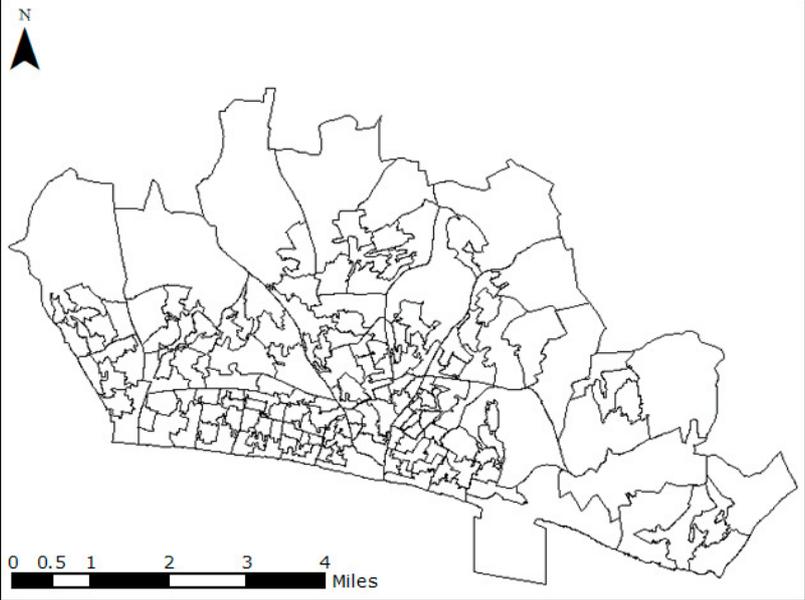
(c) Middle Layer Super Output Areas (MSOAs)
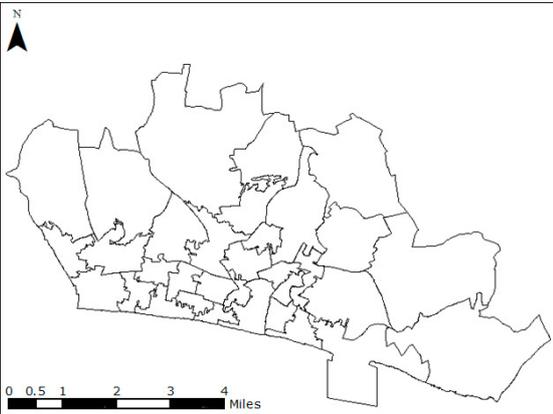
Figure 4.2: Ward and SOA geographies of Brighton and Hove

The LSOA map of Brighton and Hove is shown at higher resolution than the other two maps so that all SOA boundaries are visible.

By comparing panels (a) and (b) of Figure 4.2 it is possible to identify the constituent LSOAs of each ward. A comparison of the ward and MSOA maps in panels (a) and (c) reveals that the LSOAs were quite differently aggregated to form MSOAs. Just one of the 33 MSOAs is identical to one of the 21 wards (the Woodingdean ward).

4.2   The uneven geographies of children and young people on the Compass

Most of the secondary datasets considered later in this chapter report only on children and young people in a single age-grouping of 0-16 years. Therefore in this chapter Compass data analysis was also restricted to under 16 year olds. Analysis of the Compass dataset, in mid-2008 reveals, 832 disabled under 16 year olds living in Brighton and Hove. A ward map of the data is presented in Figure 4.3.
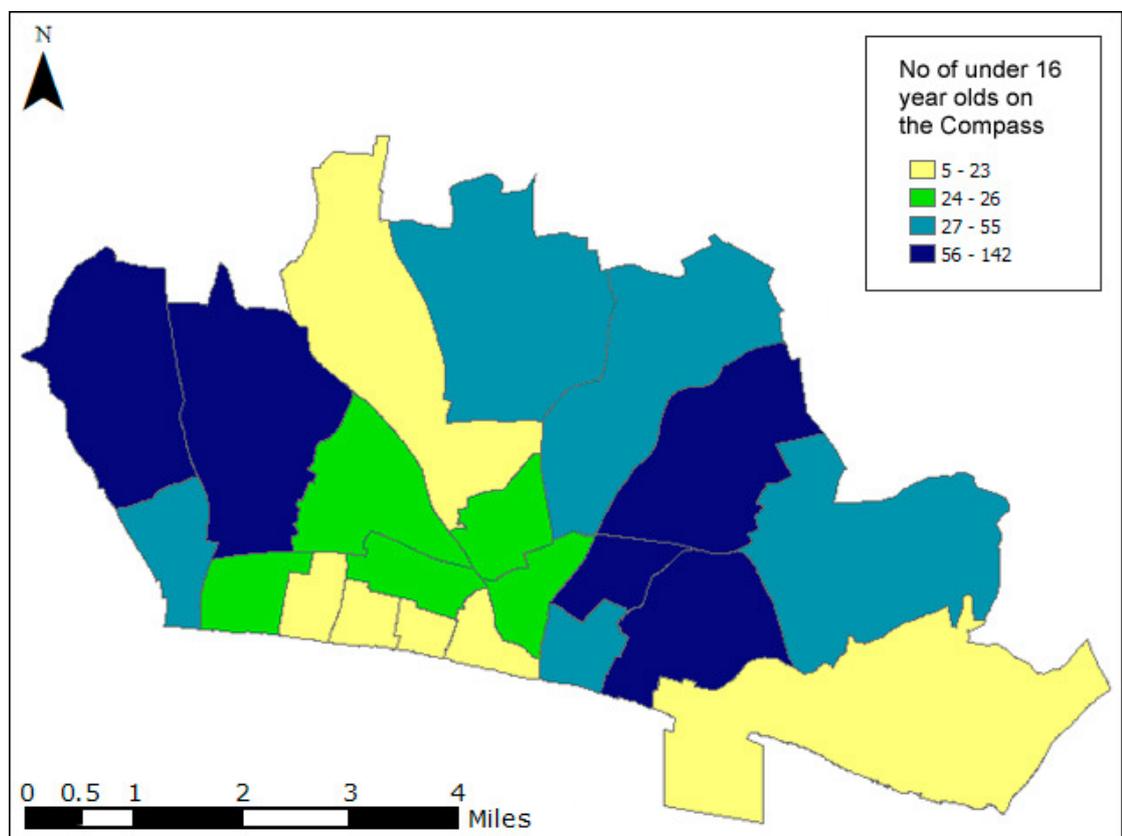
Figure 4.3: Numbers of under 16 year olds on the Compass mapped by ward

Wards ranking in each quartile of the population distribution are indicated.

The map in Figure 4.3 reveals that there are very different numbers of under 16 year olds on the Compass in different wards of the city. The numbers peak in an eastern tract and in the north west of the city. However, the peak number in the eastern tract (Moulsecoomb and Bevendean ward – 142 children) is considerably greater than that in the north west (North Portslade ward – 58 children). The numbers are lower in wards radiating outwards from these two foci and lowest in Rottingdean Coastal (in the east), Withdean (a central inland ward) and in the central seafront wards.

Next the numbers of under 16 year olds on the Compass were mapped by SOA. The numbers ranged from none to 31. The vast majority of SOAs (134 of the 164 SOAs) had 7 or fewer under 16 year olds on the Compass (were in the bottom quartile of the range of values). In 11 of these SOAs (10D, 15B, 20B, 24E, 27A, 28B, 29A, 29B, 29D, 31B, 31E), which are all close to the centre and seafront, there were no under 16 year olds on the Compass. 20 SOAs had between 8 and 15 under 16 year olds on the Compass, and 7 had between 16 and 23. Only 3 SOAs were in the top quartile of the range of values. These are LSOAs 9C, 25B and 25C. A map of this data is shown in Figure 4.4. A linear scale is used because the numbers of under 16 year olds per SOA was so uneven. The ward locations of the three SOAs with values in the top quartile of the range are indicated in the inset panel in Figure 4.4.

Figure 4.4 shows that two of the three SOAs with values in the top quartile of the range are adjacent to one another and are towards the centre of the East Brighton ward, whereas the other lies within the Moulsecoomb and Bevendean ward.

The SOA level mapping highlights that under 16 year olds on the Compass are very unevenly distributed in different areas of the city. Particular areas within the east of the city, especially within the East Brighton and Moulsecoomb and Bevendean wards, contain the highest numbers. No SOAs in the west of the city contain more than 15 children and most others contain five or fewer children. There are 11 SOAs with no children on the Compass and these are mainly located centrally and close to the seafront of the city.
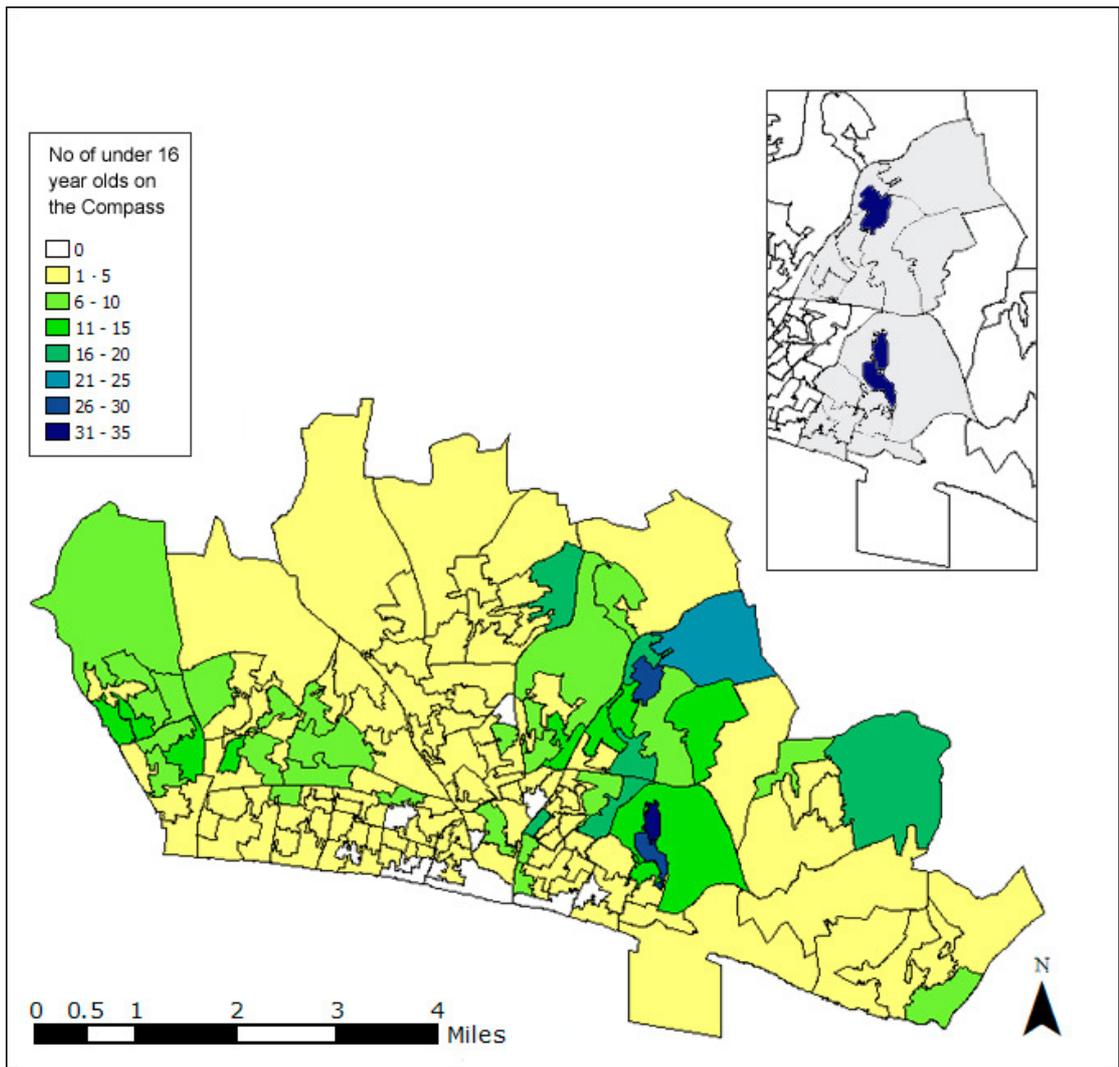
Figure 4.4: Numbers of under 16 year olds on the Compass mapped by SOA

In the inset panel, the three SOAs with values in the top quartile of the range are shaded dark blue. Other SOAs comprising the wards they are in are shaded grey.

However as registration on the Compass is voluntary, these children and young people do not represent all the disabled under 16 year olds in the city and it is possible that particular cohorts, with certain kinds of disabilities, or of particular age ranges or living in specific areas of the city, will be under represented. Unfortunately, key documents relating to local children, such as Brighton and Hove's current Children and Young People's Plan (Brighton and Hove Children and Young People's Trust, 2006), largely ignore demography. The only demographic information on disabled children is a brief allusion to reported findings from the Compass that the majority of disabled children live in the more deprived areas of the city. Therefore in the next two sections the possibility that

secondary datasets exist that represent disabled children and young people across the city, or at least complement data from the Compass, is explored.

4.3   Secondary datasets that might help elucidate the small area geographies of childhood disability

The major datasets that potentially relate to the population of disabled children are as follows:

1. The numbers of Disability Living Allowance (DLA) claimants

The numbers of DLA claimants have been published online by the Department for Work and Pensions (DWP) at quarterly intervals since May 2002. The datasets are archived at http://83.244.183.180/NESS/BEN/dla.htm. The data is collated at SOA and at ward level. However, the numbers are rounded up or down to the nearest 5 people per SOA or ward. The numbers of claimants are categorised by age and the youngest age group considered is under 16 year olds. DLA can be awarded at a lower or higher rate for help with mobility, and/or at a lower, middle or higher rate for help with care. Although information on gender and level of DLA award is provided in this dataset, it is only reported for all claimants, so further information about under 16 year olds, or, indeed, any other age group is not made available.

2.   Census data on the numbers of people with a limiting long-term illness (LLTI)

The 2001 Census contained the question:

"Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?"

Guidance was given to: "Include problems which are due to old age."

Adults were asked to self-assess whether they had a LLTI. However, in the case of children, householders were asked to make the assessment.

Data is published for under 16 year olds, by gender and age groups (0 to 4, 5 to 7, 8 to 11 and 12 to 15 years old). It is collated at SOA level, but access to the data is restricted. It is available via CasWeb (http://casweb.mimas.ac.uk/), as part of the census aggregate statistics, and registration and use of the data is restricted to academic users. Moreover, data from the 2001 Census is now 8 years old, so is quite out of date.

3. Census data on the people's current health status

The 2001 Census contained the self-assessment question:

"Over the last twelve months would you say your health has on the whole been: Good? Fairly good? Not good?"

As with the census question on limiting long-term illness, children's health status was assessed by the adult householders. The data for under 16 year olds is available via CasWeb (http://casweb.mimas.ac.uk/), and it has been further subdivided by gender and age. As with the question on LLTI, the data on current health status has been collated by SOA.

4. Numbers of Low Birthweight Live Births

Low birthweight babies are at greater risk of disability. Data is made available by the ONS on the Neighbourhood Statistics website and by the NHS via the Compendium of Clinical and Health Indicators (www.nchod.nhs.uk). But only data at local authority level and higher geographies is made publicly available; data for smaller geographical reporting areas is only available to medical specialists.

5. The Schools' Census - England

The DCSF conducts an annual Schools' Census covering all schools, including maintained (and grant-maintained) nursery, primary, secondary and special schools, non-maintained special schools, Pupil Referral Units and independent schools. Data are collected on pupils (full-time and part-time) by age and sex, number of pupils with special educational needs, number of pupils in nursery classes in primary schools, admissions, teachers, non-teaching staff, classes, lesson time, courses of study of pupils aged 16 and over, school meals and the number of boarding pupils. Some Schools' Census data are made publicly available at local education authority and regional level but not at school, SOA or ward level.

6. Children with special educational needs (SEN)

Approximately one in five children are recognised by their schools as having special educational needs. At the time of the 2007 Schools' Census Brighton and Hove reported 3,952 children on School Action, 2,123 on School Action Plus and 1,169 with Statements of SEN. School Action and School Action Plus are SEN strands of action that are used to identify pupil needs prior to a child having a full statutory assessment of their SEN. Most disabled children have SEN. However, although the majority of severely disabled children have statements, a significant proportion of less severely disabled children do not. The DCSF reports on the numbers of children with SEN and the types of need (Statements of SEN are allocated primary need categories). But these reports are only made publicly available for local education authority level or higher geographies. Over recent years there has been a drive to reduce the numbers of children with statements of SEN. Summary data for 2001-2007 revealed that the proportion of children with statements in Brighton and Hove had fallen from 4% (1,422 children) in 2001 to 3.3% (1,169 children) in 2007.

7. Family Fund data

The Family Fund (www.familyfund.org.uk) can award grants to families with a severely disabled child aged 17 or under, who meet all of the following eligibility criteria:

- the household's income (before tax and excluding any overtime) is £23,000 per year, or is entirely from benefits,
- the applicant has less than £18,000 in savings, and
- the applicant has permanent residency in the UK and has lived in the UK for six months.

Thus the Family Fund hold data on a subset of disabled children with relatively severe difficulties/complex needs and living in low-income families, whose parents/carers have applied for grants.

In 2003 the Family Fund knew of 409 children in Brighton and Hove (personal communication, M. Woolley). At that time approximately 1,225 under 16 year olds in Brighton and Hove were receiving DLA.

Of the datasets described above, only the first three (on DLA claimants and on the two health-related 'self-assessment' questions from the 2001 Census) are published at small area level.

Although not all disabled children have (recognised) SEN and schools record a child's SEN only by a single 'primary need' category, if Schools' Census data, and other SEN-related data collected by local schools, were made available at small area level, these could provide valuable complementary data to Compass data. National SEN data reveals that children on schools' SEN registers are over twice as likely to be eligible for free school meals as those who are not (ONS, 2008). If small area level data were available, the question of whether the local geographies of SEN are uneven could be comprehensively addressed. Similarly, if data on the numbers of low birthweight babies were available at small area

level this might serve as a valuable proxy indicator for investigating the local geographies of childhood disability.

The Family Fund holds data on a rather restricted subset of Brighton and Hove's disabled children and young people (those with more severe or complex disabilities who live in lower income families, and whose parents/carers have applied for grants). In 2003 it held information on 409 children and young people in Brighton and Hove. The equivalent number on the Compass (in mid 2008) was 958 under 18 year olds on the Compass. As it likely knows of less than half the number of children and young people on the Compass it is not considered any further.

In the following section, the potential use of the 2001 Census questions on LLTI and current health status, and of data on DLA claimants, as indicators of childhood disability are further explored.

4.4 Relevance of data on DLA claimants, 'limiting long-term illness' and 'current health status' to studies of childhood disability in Brighton and Hove

The last major study into childhood disability by the Office of Population and Census Surveys (OPCS) was conducted in the mid 1980s and the findings suggested that about 3% of the UK's children were disabled (Bone and Meltzer, 1989). There has been no similarly detailed study since. However, the Prime Minister's Strategy Unit (2005) analysed data from the 2002 General Household Survey [that had been reported by Rickards *et al.* (2004)] on the numbers of people reporting limiting longstanding illness or disability. They found that, since 1975, the increase in numbers had been faster for children (aged 0-16) than working age or retired people. The numbers had risen from 476,000 children in 1975 to 772,000 in 2002. This number, which equated to 7% of the 2002 child population, had increased by 62% since 1975, whereas the numbers of adults reporting impairments had only increased by 22%. The dramatic increase appears

to be due largely to two main factors. The first is the improved neonatal care and associated survival of very low birth-weight babies or young children with very complex special needs. The second is the marked increase in the incidences of children and young people diagnosed with autistic spectrum conditions and mental health conditions.

According to the 2001 Census Theme Table On All Dependent Children, CT001, 4.9% (2,016) of the under 16s in Brighton and Hove were reported as having limiting long-term illness (LLTI), whereas only 1.47% (605) of them were reported as having 'not good health' (NGH).

As the numbers of children reported to have NGH are very low, the reporting of 'current health status' appears to offer little prospect for revealing the numbers of disabled children. Indeed, although some disabled children, including many of those with complex medical needs, often experience poor health, others usually have good general health. This latter group could include many children with learning difficulties, autistic spectrum conditions and mental health conditions, and even children with some (episodic) chronic health conditions.

For many disabled children the diagnosis of additional needs occurs during early to mid childhood. Diagnosis can be even later, for example for children whose special needs become most apparent when they make the transition from primary to secondary schooling. Only in a minority of cases is a diagnosis made at or shortly after birth. As the table CT001 includes a breakdown by age group of the numbers of children with LLTI or NGH, the percentages of children of increasing age in Brighton and Hove at the time of the 2001 Census who were reported to have LLTI or NGH were calculated. For comparison, the percentages of children of increasing age that were on the Compass (in mid-2008) were calculated. The results are summarised in Figure 4.5.

Figure 4.5 shows an increase in the percentage of children reported to have LLTI, and on the Compass, in older age groups. However the percentages of children reported to have 'not good health' does not increase with age, reinforcing the view that it is unlikely to be of use as an indicator of childhood

disability. The shapes of the distributions of reported LLTI and Compass membership are compatible with both reflecting disability but the latter including a time lag for the majority of the disabled children between parental concern and diagnosis.
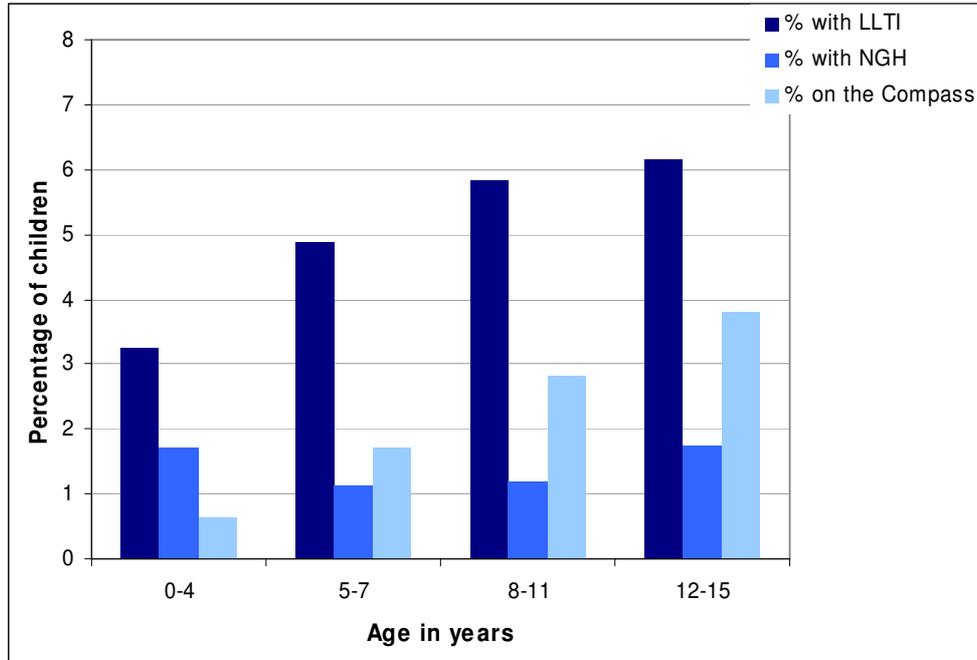
Figure 4.5: The percentages of children in Brighton and Hove with LLTI, NGH, and on the Compass

A map showing the numbers of children and young people aged under 16 per ward who were reported to have LLTI at the 2001 Census is shown in Figure 4.6. The map shows that the numbers of under 16 year olds reported to have LLTI at the time of the 2001 Census were very uneven in different parts of the city. The pattern is related to that for under 16 year olds on the Compass (Figure 4.3), with wards ranking in the top quartile mapping within an eastern region, and in the north west. The wards with the highest numbers of under 16 year olds reported to have LLTI were Moulsecoomb and Bevendean ward (285 children), East Brighton ward (193 children) and Hangleton and Knoll ward (172 children).
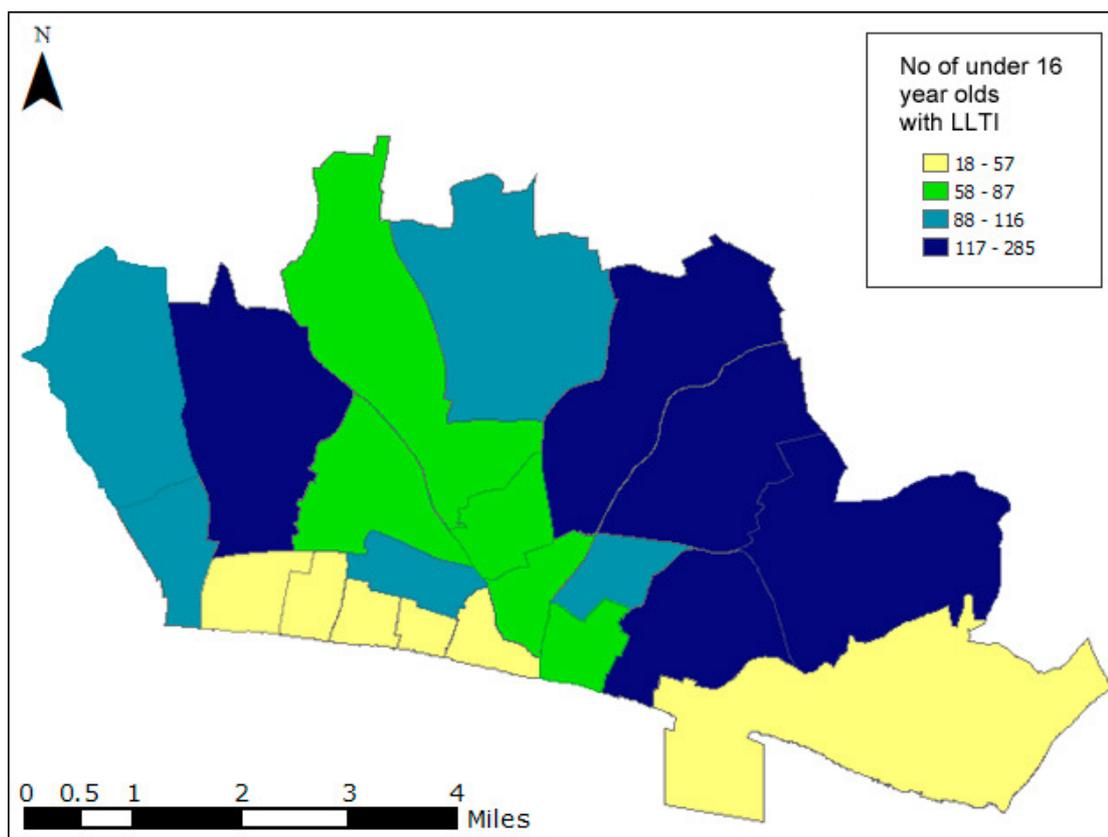
Figure 4.6: Numbers of under 16 year olds in Brighton and Hove with LLTI mapped by ward

In May 2002 (the earliest time point for which the numbers were published) 1,130 under 16 year olds in the Brighton and Hove were receiving DLA. Less than a year earlier, 2,016 under 16 year olds had been reported to have LLTI. The finding that only about half the number of under 16 year olds received DLA as were reported to have a LLTI might suggest to a lay person that parental reporting of children with LLTI cannot be synonymous with childhood disability. But there is a caveat: take up of disability living allowance (DLA) is known to be low. In a follow up study to the Family Resources Survey, Craig and Greenslade (unpublished observations, 1998) found that only between 40-60% of disabled 16 to 24 year olds were claiming DLA (they did not investigate the take up rate for under 16 year olds). The complexity of the application for claiming DLA, the geographical patchiness of information and advice about claiming, the high rate of poor decisions by the DWP on applications, and the stigma and shame of applying for benefits all contribute to this. Various surveys suggest that only

around a half of disabled children are awarded DLA, with disabled children from socially disadvantaged families being less likely to get DLA and less likely to be awarded the higher rate. In a detailed study of 138 children with Down syndrome, Ellis *et al*. (2008) found that children from ethnic minority families (and those speaking English as a second language) were less likely than other families to be granted DLA or to be awarded the higher rate. They also found no evidence that granting of DLA was related to the severity of the child's disability.

The table CS021, entitled Economic Activity by Sex and Limiting Long-Term Illness (LLTI), provides information on 16 to 74 year olds with LLTI. Although not directly relevant to studies on children, the data reported here can be used to compare the numbers of 16 to 74 year olds reporting LLTI with those classified as permanently sick or disabled. The data for Brighton and Hove is summarised in Table 4.1

Table 4.1: LLTI and economic activity of 16-74 year olds in Brighton and Hove

Economic Activity	Number of people	Number of people with LLTI	Percentage of people with LLTI
All people	185093	29933	16%
All economically active people:	125538	8937	7%
Employed part-time	26268	2545	10%
Employed full-time	85075	5010	6%
Unemployed	6776	1042	15%
Full-time student	7419	340	5%
All economically inactive people:	59555	20996	35%
Retired	21098	7747	37%
Student	13130	701	5%
Looking after home/family	10501	1386	13%
Permanently sick or disabled	9738	9438	97%
Other	5088	1724	34%

Almost all (97%) of the 9,738 people who were classified as permanently sick or disabled considered themselves to have a LLTI. However, they made up only about a third of the 29,933 people who reported having a LLTI. In May 2002 7,380 16 to 59 years olds and 8120 people aged 16 and over were getting DLA in Brighton and Hove. (The datasets reporting the numbers of DLA claimants are split into different age groups to those used in the census tables, making direct

comparisons for 16-74 year olds impossible.) So if self-reported LLTI is broadly synonymous with disability, this would mean that over two-thirds of disabled people failed to claim it.

In May 2002 there were approximately 1,130 under 16 year olds in Brighton and Hove receiving DLA (numbers per ward are rounded up or down to the nearest 5). In Figure 4.7 a ward map of the data is shown.
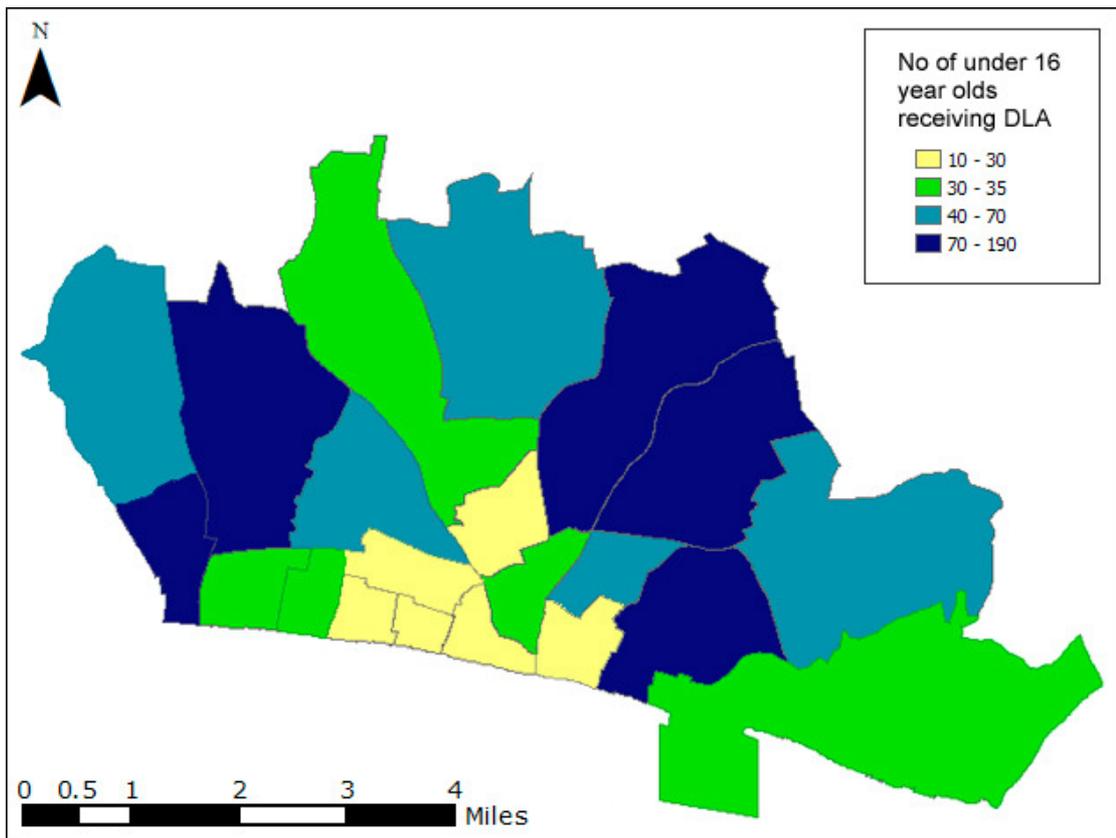
Figure 4.7: Numbers of under 16 year olds in Brighton and Hove receiving mapped by ward

The map shown in Figure 4.7 has overall similarity to that for under 16 year olds reported to have LLTI at the time of the 2001 Census (Figure 4.6) and under 16 year olds on the Compass (Figure 4.3) with wards in the top quartile mapping within an eastern region, and in the north west. The wards with the highest numbers of under 16 year olds receiving DLA were Moulsecoomb and Bevendean ward (190 children), East Brighton ward (130 children). The other wards ranking in the top quartile had 90 or fewer claimants.

4.5   Conclusions

In this chapter geographic mapping of Compass data, at ward and SOA level, has revealed that there are very large differences in the numbers of under 16 year olds on the Compass in different parts of the city. The wards ranking in the top quartile map in two areas: one in the east of the city and the other in the west. Mouslecoomb and Bevendean ward and East Brighton ward contain the highest numbers, whereas the numbers in the wards in the west are much lower. Finer level mapping reveals that there are very few children on the Compass in the majority of SOAs of Brighton and Hove, but that the numbers are high in particular SOAs, especially within the Mouslecoomb and Bevendean ward and East Brighton ward.

As the Compass does not represent all disabled children in the city, several secondary datasets that might potentially be relevant to childhood disability were explored further. Some datasets were only made available to specialist users at ward or SOA level. The numbers of under 16 year olds receiving DLA, and under 16 year olds reported to have LLTI, which were available at ward and SOA level, showed related (and very uneven) distributions within Brighton and Hove wards. It is reasonable to assume that the unevenness of the local distribution of such children and young people is unlikely to be a phenomenon confined to Brighton and Hove. In turn, the analysis of other datasets relevant to childhood disability at small area level could be crucial to understanding the processes that impact on uneven geographies of childhood disability locally. A rich dataset is compiled through The Schools' Census and, if the data was published at small area level, it could provide valuable local information on children with SEN, many of whom are disabled. For example, in their annual reports on permanent and fixed period exclusions from school (see ONS, 2008), the ONS reports national level data on pupils with and without SEN. This includes the numbers of boys and girls with SEN, from which it can be calculated that 65% of pupils with SEN are male. It also reports on the numbers of pupils who are eligible for free school meals, revealing that 27% with SEN but only 12% without SEN are eligible for free school meals.

In the datasets on DLA claimants, only the total numbers of under 16 year olds per ward or SOA were reported, so few comparisons between this and the other datasets were possible. For the dataset as a whole (which covers claimants of all ages), further breakdowns are available, such as gender, finer age-groupings, and the level and duration of the DLA award. Perhaps less consideration and importance has been given to the data on under 16 year olds, because children are rarely considered as a subject group in their own right (McKendrick, 2001).

The Compass cannot adequately capture the whole local population of disabled children. Even with targeted promotion and incentivised registration, disabled children living in the more deprived areas, are likely to be under-represented on this voluntary registration database. Amongst such voluntary registration databases, the Compass represents a relatively high proportion of local disabled children, but it probably does not represent the majority of local disabled children. However even if registration was compulsory, coverage would still be incomplete because some parents/carers do not recognise or consider their child to be disabled.

The numbers of under 16 year olds receiving DLA somewhat exceeds the numbers on the Compass. However, it is known that there are significant barriers to successfully claiming DLA and it is thought that about half of disabled children do not receive it. For both children and adults, research suggests that the more socially excluded people are, the less likely they will be to successfully claim DLA. Amaze provides a service that supports local parents/carers to make claims for DLA for their disabled children. This service is inundated with requests for support. It tries to direct its support towards the more disadvantaged families. Of 255 new DLA claims it assisted with in 2007-08, almost half of the households were single parent households, one fifth identified themselves as non-English speaking, and about 50% of parents themselves had chronic health needs or were disabled (Amaze, 2008).

Kyffin (2006) found marked inequalities in LLTI rates for adults in different local authorities in the South East. (Age-standardised) LLTI rates were strongly correlated with mortality rates, and even more strongly with deprivation levels.

At ward level there was a strong association between the percentage of people aged 40-49 and 50-59 claiming incapacity benefit or severe disablement allowance and the proportions reporting LLTI. These findings are compatible with self-reported LLTI reflecting real and significant health problems. But it is possible that this is an ecological fallacy – the people with poor health might not be the ones reporting LLTI.

Kyffin noticed that the association between LLTI rates and the proportions of people claiming incapacity benefits was less clear in younger and older age groups. This could mean that LLTI or disability/incapacity benefits claims (or both) less accurately reflect ill health for children and older people than for working age people. Moreover, although the census question on LLTI is self-assessed for adults, parents or carers answer the question on behalf of their children. Waters *et al*. (2000) investigated the effects of parents' gender and their own health status on their propensity to report on their child's ill health. They found that mothers, but not fathers, who self-reported poor health, had increased odds of reporting their children with poor health. Given these limitations of subjectivity and relevance, it is perhaps remarkable that there is similarity between the geographic distributions, gender bias and age distributions of reported LLTI, and Compass membership.

In the absence of good indicators of childhood disability, it would probably be useful for any local authority that is considering how to resource services for disabled children to map the numbers of children receiving DLA and reported to have LLTI. The former will substantially underestimate the number of disabled children in each area, while the latter may very roughly approximate to (or towards) it.

As the Compass, DLA and LLTI datasets all revealed related, highly uneven geographies for under 16 year olds in Brighton and Hove, the focus of the next chapter is on identifying the reasons for this irregular distribution.

Chapter 5

A Demographic Analysis of Brighton and Hove Focusing on Children and Young People

Introduction

This chapter examines the demographic profile of Brighton and Hove based on analyses of both the Indices of Deprivation (ID) 2007 and 2001 GB census data. The primary aim is to provide a concise demographic profile of the city compared to other local authorities in the South East. This is an important objective since geographies of ill health are linked to geographies of deprivation and poverty and to geographies of environmental hazards. A brief commentary of the whole population is included, with a particular focus on children and young people. The geographies of children and young people living in income deprivation are shown to be uneven. Cluster analysis, an exploratory technique, is used to explore whether there may be different socio-economic groups of families (with dependent children) within the city. As disabled children are more likely to live in poverty and to experience social exclusion than non-disabled children (Chapter 1), these analyses are important for contextualising the uneven geographies of childhood disability in Brighton and Hove reported in the previous chapter.

5.1   Brighton and Hove in the context of the South East Region

In this section an overview of deprivation within the South East Region of England is presented. Recent ID exercises reveal the South East to be the least deprived region overall in England. In Figure 5.1 a chart showing the proportions of LSOAs in each region that rank in the top and bottom quintiles for their IMD 2007 scores is shown.
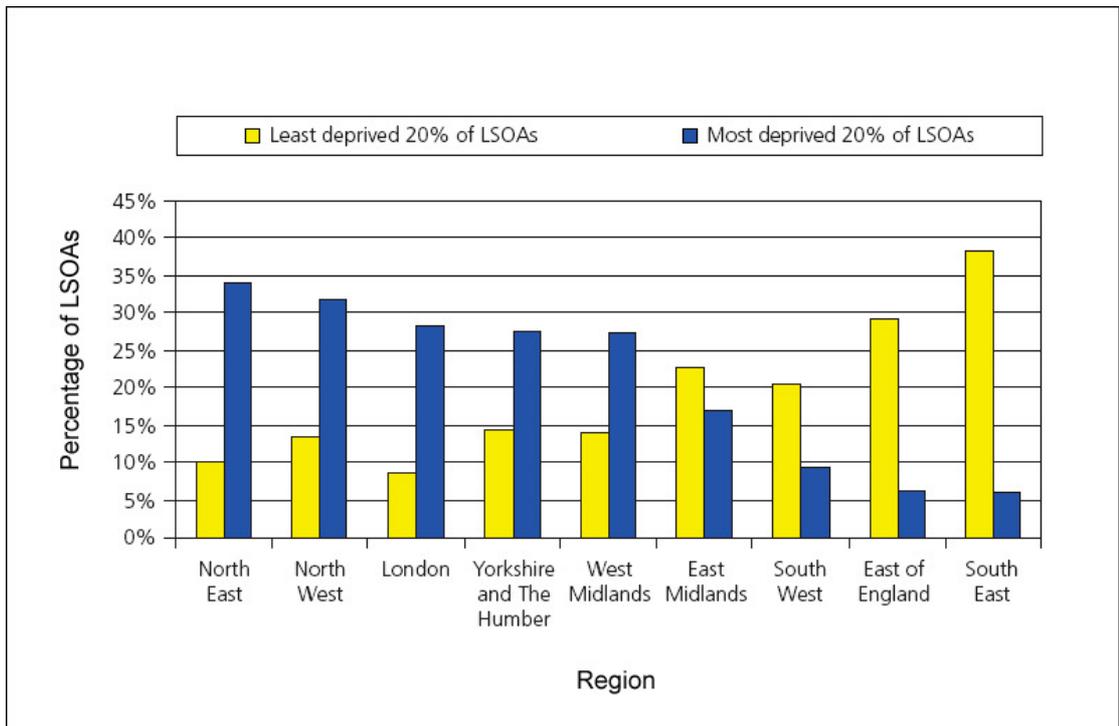
Figure 5.1: Percentages of LSOAs per region that rank in the most and least deprived IMD quintiles

Reproduced from Noble *et al.*, 2007.

Figure 5.1 shows that the South East has a higher percentage of its SOAs in the least deprived quintile of English SOAs, and a lower percentage in the most deprived quintile, than all other regions.

However, whilst it is the least deprived region overall, there are some areas of relatively high deprivation within the South East. In the ID 2004 exercise the four most deprived local authorities in the South East were Hastings, Brighton and Hove, Thanet, and Portsmouth. Out of the 354 English local authorities, Hastings ranked as the 38th most deprived and Brighton and Hove ranked 83rd.

Analyses of the ID 2007 also revealed pockets of deprivation in the South East that are largely confined to coastal local authorities. This is evident from the map shown in Figure 5.2.

Figure 5.2: The Index of Multiple Deprivation 2007 for the South East Region
Reproduced from Noble *et al.*, 2007.

In fact pockets of coastal deprivation also exist in the other regions (for example, Communities and Local Government Committee, 2007 and Smith, 2009). But, in the IMD maps presented by Noble *et al.* (2007), the pockets are most obvious in the South East because this region it has the lowest overall level of deprivation.

In the ID 2007 Hastings ranked 31st and Brighton and Hove ranked 79th most deprived amongst the English local authorities. Both therefore ranked worse, relative to all the other English local authorities, than they had done in the previous ID exercise. As discussed in Chapter 3, an increase in the ranking of a local authority could have occurred because of absolute changes in the deprivation in other local authorities. So we cannot unreservedly conclude that Hastings and Brighton and Hove have become more deprived, in absolute terms, between the time of the ID 2004 and the ID 2007 exercises.

Dorling and Rees (2003) reported a longitudinal analysis of social polarisation in Britain, based on comparing key statistics from the 2001 Census with those from the 1991 Census (and on more limited comparisons with 1981 and 1971 census data), for every local authority. They assessed the extent to which groups were spatially polarised by developing an index of segregation, which measured the percentage of people who would have to move in order to remove all segregation. They found that, since 1991, there has been a rise in social polarisation of districts. For example, there has been spatial polarisation by age: whereas in 1991 8% of 20-24 year olds would have had to move to even out their distribution, in 2001 this figure had increased by 46% to 12%. They also found that major rises in geographical segregation had occurred for married people, white people, migrants, (outright) home-owners and the poorest households. The authors concluded that they were witnessing: "...the continued division of the country into areas now more easily than ever typified as being old and young, settled and migrant, black and white, or rich and poor" (Dorling and Rees, 2003: 1287).

The finding that over recent years Brighton and Hove (and Hastings) have become relatively more deprived, is in keeping with the picture of increasing geographical separation of different social groups and decreasing social mobility.

Although we cannot be certain whether Brighton and Hove, the subject of this study, and Hastings, the most deprived local authority in the region, do actually have greater levels of deprivation than they did three years ago, they both currently rank within the most deprived quartile of local authorities in England (and Hastings ranks within the most deprived decile).

It will likely come as a surprise to many, who may be most familiar with images of its tourist attractions, to learn that Brighton and Hove ranks within the most deprived quartile of English local authorities. Similarly, those who have heard about the process of gentrification in Hastings Old Town and who are familiar with its quaint 'picture postcard' image, may be surprised to learn that Hastings ranks in the most deprived 10% of local authorities in England.

5.2   The Child Population of Brighton and Hove

As the population of disabled children of Brighton and Hove is the focus of this thesis, it is important to view the child population within the context of the overall population of Brighton and Hove. Therefore in this section the distribution of individuals within the city by broad age groups is explored. The mid-year population estimates, published by the Office for National Statistics (ONS) for 2005, were the source of the population data used here.

In Figure 5.3 the distribution of people within Brighton and Hove is mapped and then compared to the distributions of under 16 year olds, working aged people and those of pensionable age. As the aim was to provide an overview of the population distributions, mapping was done by MSOA (rather than LSOA). MSOAs corresponding to the four quartiles of the population distribution range are indicated.

(a) Total numbers of people in Brighton and Hove MSOAs
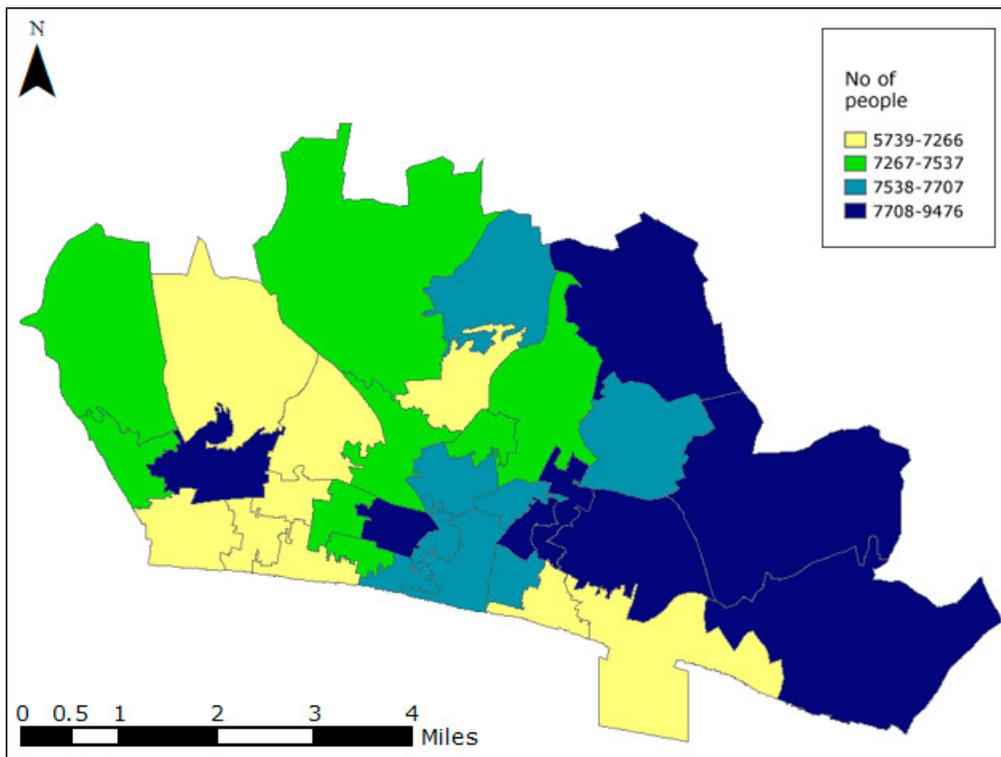
(b) Numbers of people of pensionable age in Brighton and Hove MSOAs
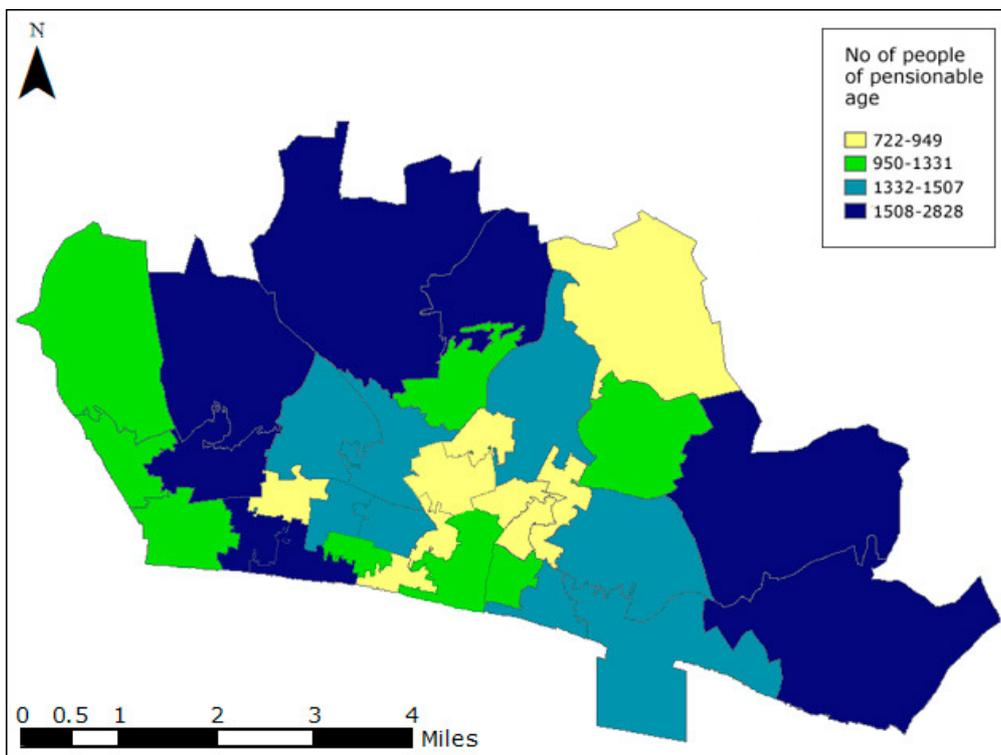
(c) Numbers of working-age people in Brighton and Hove MSOAs
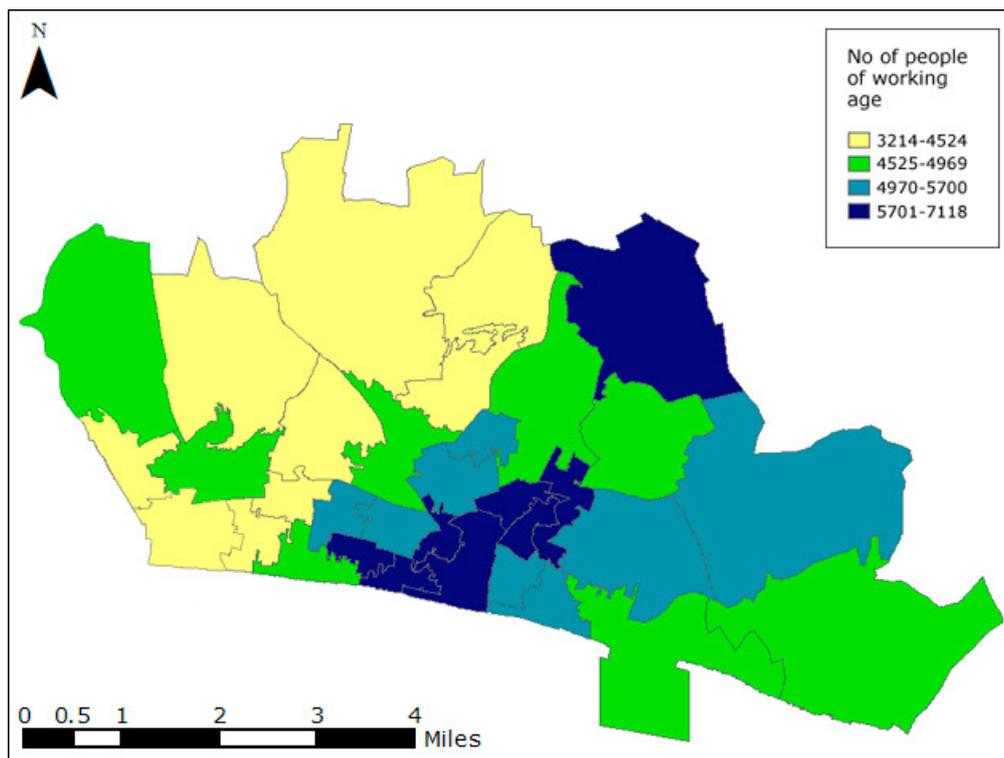
(d) Numbers of children and young people aged under 16 in Brighton and Hove MSOAs
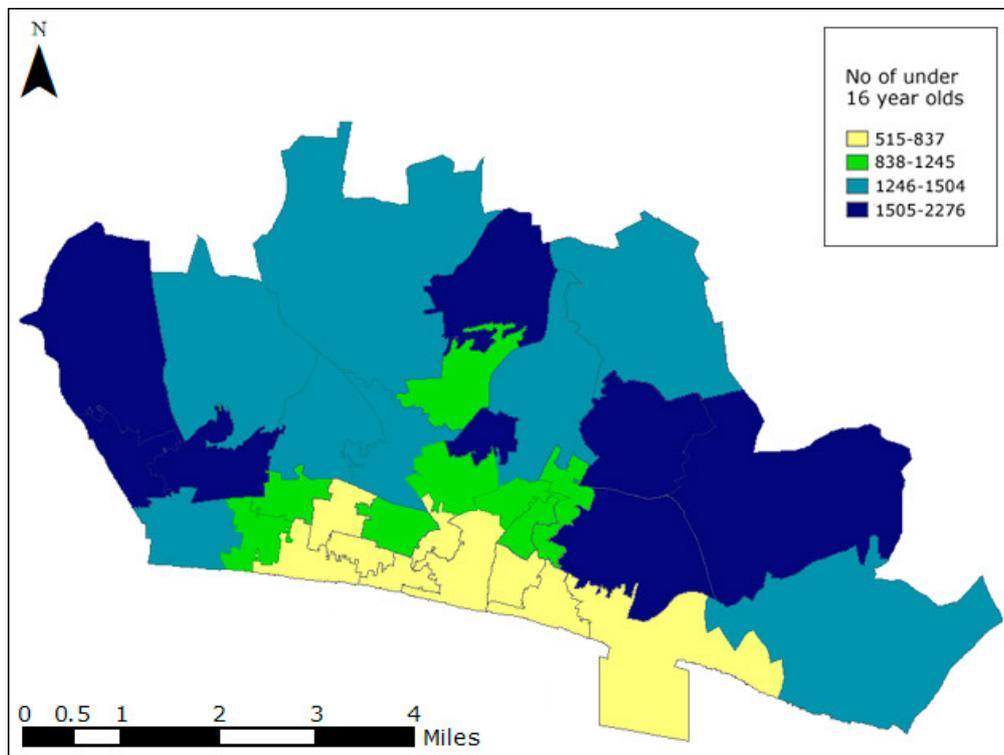
Figure 5.3: Numbers of people in Brighton and Hove mapped by MSOA

Figure 5.3(a) shows that broadly speaking, MSOAs in the east of the city have greater numbers of inhabitants than those in the west. There is some variation in the numbers of people in different MSOAs. The range is from 5,739 to 9,476 people; so the most highly populated MSOA has 1.65 times as many people as the least populated.

The maps shown in Figure 5.3 reveal that the patterns of where under 16 year olds, people of working age, and people of pensionable age live are distinct and different. In the case of under 16 year olds, the age group this thesis focuses on, the numbers are lowest in MSOAs in the central seafront area. They tend to increase with increasing distance from the city centre. But superimposed on this pattern, there are two major areas, in the east and the west of the city with relatively high numbers of under 16 year olds. The three MSOAs with the highest numbers of under 16 year olds make up the eastern region shown in dark blue in Figure 5.3d.

This map provides the first clue to why the geographies of childhood disability are so uneven in Brighton and Hove. Which is simply that the numbers of under 16 year olds are considerably higher in the east and west of the city than elsewhere.

It is noteworthy that, although the total number of inhabitants of each MSOA is similar (Figure 5.3), within each of the three broad age groups, the range in the numbers of people per MSOA is more variable. In the case of people of working age (panel c), the highest value is 2.2 times that of the lowest. For people of pensionable age (panel b) it is 3.9. And for under 16 year olds (panel d) it is 4.4. This is potentially important information for planners of children's services in Brighton and Hove. If they planned resources assuming similar numbers of children in each SOA they would, for example, under-resource services in East Brighton and over-resource services in the central sea front area of the city.

5.3　The uneven geography of SOAs for children and young people

To investigate the variation in the numbers of under 16 year olds (and people of pensionable age) by LSOA, the range in numbers of people of all ages, under 16 year olds and people of pensionable age was analysed for the 5,319 LSOAs making up the entire South East Region. Key statistics are summarised in Table 5.1 and box plots are presented in Figure 5.4.

Table 5.1: Variation in the numbers of people in SOAs in the South East Region

Number of people	All Ages	Aged under 16	Of pensionable age
Minimum	897	48	16
10th percentile	1,281	198	150
25th percentile	1,403	242	210
Median	1,509	291	281
75th percentile	1,621	343	359
90th percentile	1,784	400	451
Maximum	7,226	1,220	1,040
Interquartile range	222	101	149
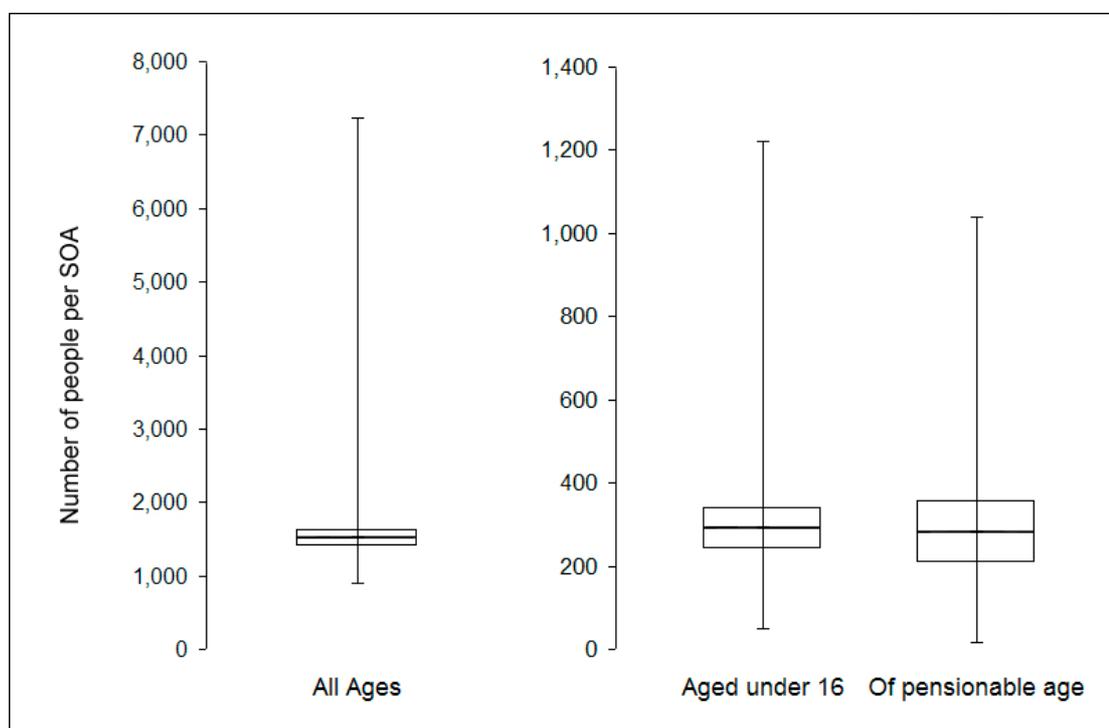
Figure 5.4: Box and whisker plots of the numbers of people in SOAs in the South East Region

The summary statistics and the box and whisker plots show that the interquartile range (and the interval between the 10th and 90th percentile) is (relatively) small for the total population. It is larger for under 16 year olds and even larger for people of pensionable age. The analysis also highlights that there are a minority of SOAs with remarkably high population counts and with low counts.

These findings are of importance to planners of children's services and older people's services and, more broadly to geographers. They highlight that whilst most SOAs (in the South East Region of England) contain relatively homogenous numbers of people of all ages, the number of under 16 year olds per SOA is more variable and the numbers of people aged 60 and over is even more variable.

It is noteworthy that in Brighton and Hove, the under 16 year olds show the greatest variation in numbers per LSOA, whereas in the South East region it is the over 60 year olds that show the greatest variation. The South East region has a higher proportion of older people than any other region, and East Sussex has a higher proportion of over 65 year olds than any other county in England. But Brighton and Hove is atypical of the South East region in that its population has a younger age structure.

5.4   Mapping the ID 2007 for Brighton and Hove

As discussed in Chapter 3, the Indices of Deprivation are the Government's official measure of deprivation at small area level. Data collection and collation exercises are undertaken and reported every few years. In the ID 2000, the geographical unit of area used was the ward. But in the 2004 ID exercise, for the first time, the SOA was used. The SOA has been used again for the recently published ID 2007. Health authorities also now collect and publish data by SOA. The intention is that, in time, all centrally reported (government) data will be published by SOA.

In the ID exercises, the deprivation characteristics of every SOA in England are scored across the seven 'domains' (income, employment, health and disability,

education, skills and training, barriers to housing and services, living environment and crime) and the SOAs are ranked in order of deprivation. SOAs in different parts of the country (within the same local authority or in different local authorities) can then be compared to one another. An 'Index of Multiple Deprivation' (the IMD), formed by combining the seven domain indices, is often used to provide a snapshot of deprivation within a local authority. Whilst the IMD provides some measure of the relative deprivation of different areas, its derivation is complex. The different indices, that have different measurement scales, are combined according to different weighting. It is also important to note that this index does not directly measure multiple deprivation.

A major reason for this massive data collection and collation exercise is that it enables pockets of deprivation to be identified, that are often obscured in ward level reporting. The rationale for the exercise is that local service planners can analyse the latest ID for their local area in order to direct their resources appropriately.

In Figures 5.5 – 5.12 the ID 2007 data for the IMD and the seven separate domain indices are mapped for Brighton and Hove SOAs. In each case the SOAs in Brighton and Hove have been ranked in order of deprivation and colour-coded depending on whether they rank in the least deprived (lightest shading) or more deprived quartiles of SOAs within Brighton and Hove.

Figure 5.5. shows that the SOAs where the highest proportions of people live in income deprivation are clustered within an eastern tract of the city and a smaller geographical area in the west. In the eastern tract, several SOAs ranking in the most deprived quartile of Brighton and Hove are flanked by those ranking in the second quartile. Two areas composed predominantly of SOAs ranking in the second most deprived quartile are close to the most income-deprived area in the west.There are a few isolated pockets of income deprivation, such as in Woodingdean (towards the Eastern boundary of the city). The two major regions where the lowest proportions of people live in income deprivation are a large, slightly west of central, inland tract and another smaller region to the east of the

marina. The Hangleton and Knoll ward contains SOAs ranking in each of the city's income deprivation quartiles.
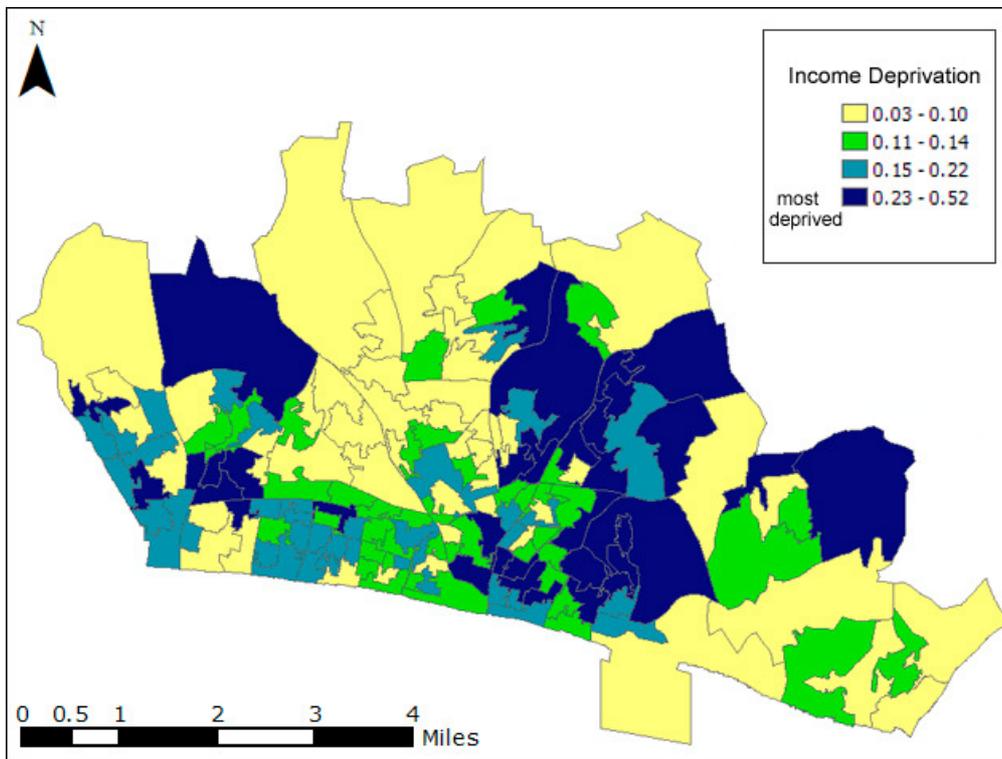

Figure 5.5: The Income Deprivation Domain scores of the ID 2007
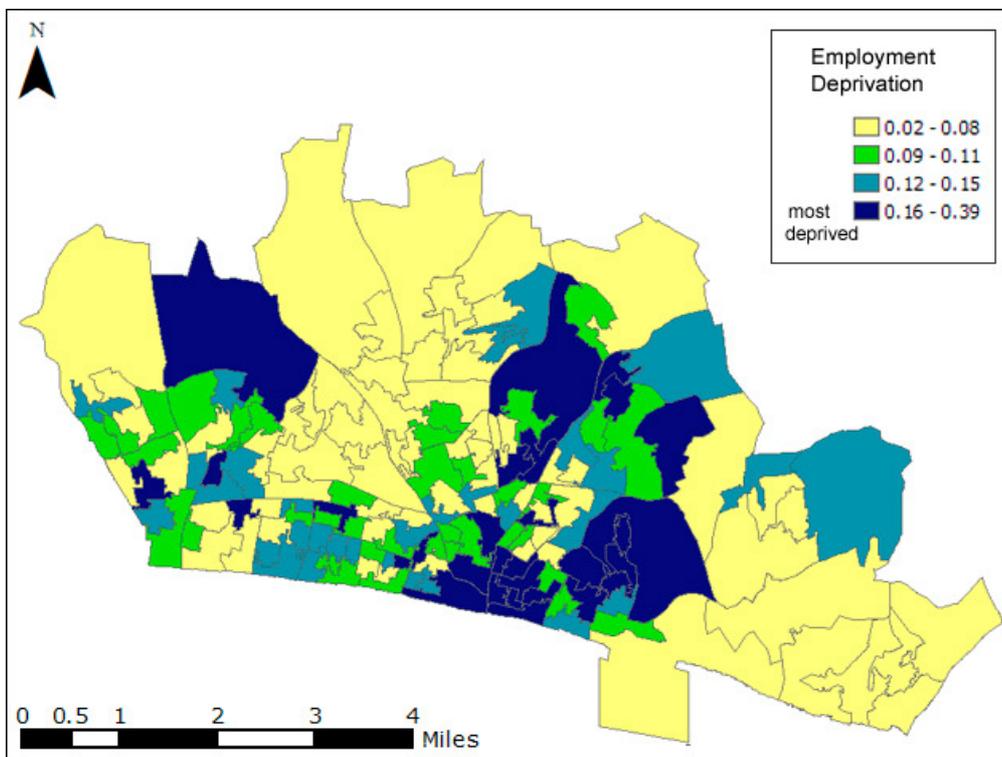
Figure 5.6: The Employment Deprivation Domain scores of the ID 2007

The pattern of employment deprivation, shown in Figure 5.6, is clearly related to that of income deprivation. However, the eastern tract is less intensely deprived and there is no western hotspot. But a new area, extending along the central seafront and inland to the mainline railway station, forms an unemployment hotspot. The majority of SOAs in least deprived quartile for employment deprivation map within the two major areas to the east and west of the eastern tract.

Mapping the Health Deprivation and Disability domain (Figure 5.7) reveals a pattern that is clearly related to that for the Income Deprivation and Employment Deprivation domains. Of the two it is arguably most similar to the Employment Deprivation domain.

Although the map shown in figure 5.8, showing the Education, Skills and Training Deprivation domain, is broadly related to the previous ones, its most striking feature is the extensive eastern tract, composed almost exclusively of SOAs ranking in the most deprived quartile. There is another western region composed only of SOAs ranking in the two most deprived quartiles, but more of its SOAs rank in the second quartile. The extremely deprived eastern region is flanked to its east and west by regions composed mainly of SOAs ranking in the two least deprived quintiles.

In Figure 5.9 the Barriers to housing and services domain is mapped. This map is dissimilar to previous ones in that some areas identified as having major barriers to housing and services map in areas that are amongst the least deprived for the income, employment, health and education domains. Other areas that are deprived map at the west and north east extremities of the city.

The three regions most affected by crime (Figure 5.10) centre on East Brighton, the central seafront region extending inland to around the mainline station, and the Hollingbury and Stanmer and Moulsecoomb and Bevendean wards. In addition, the area west of Seven Dials and parts of Withdean, Preston Park and the eastern seafront, that are in the least deprived quartile for income and employment deprivation, are in the second most deprived quartile for crime.
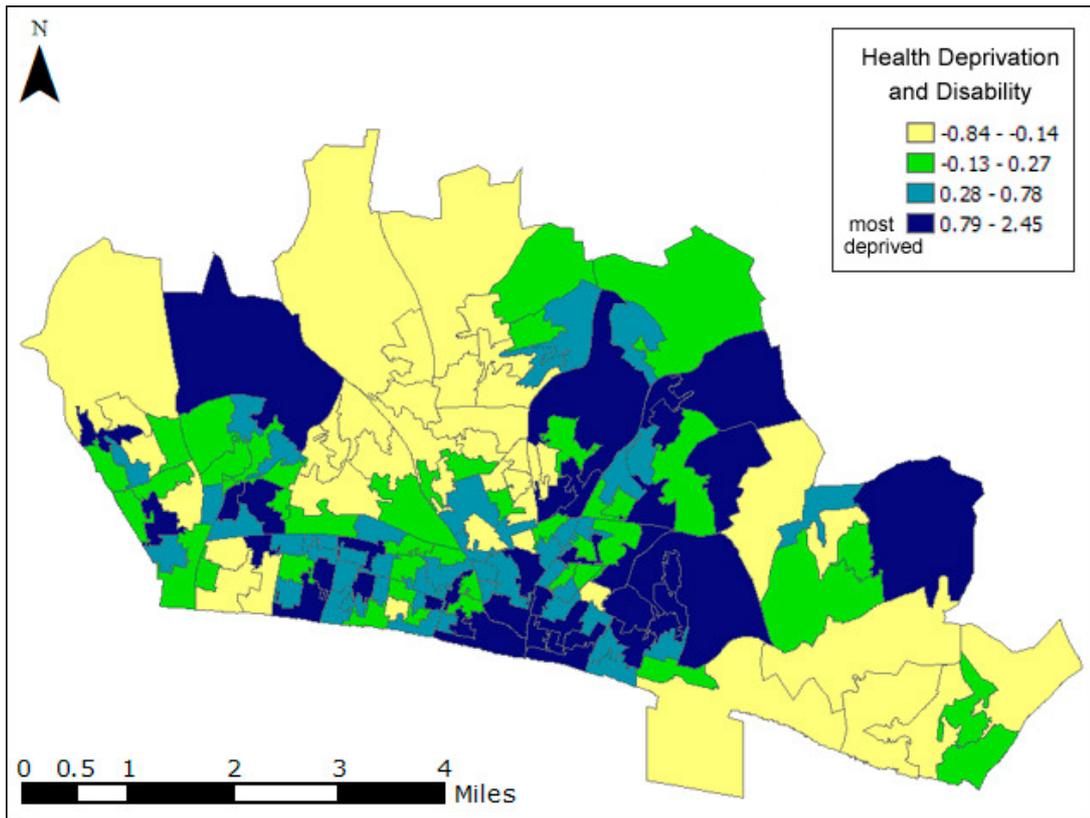
Figure 5.7: The Health Deprivation and Disability Domain scores of the ID 2007
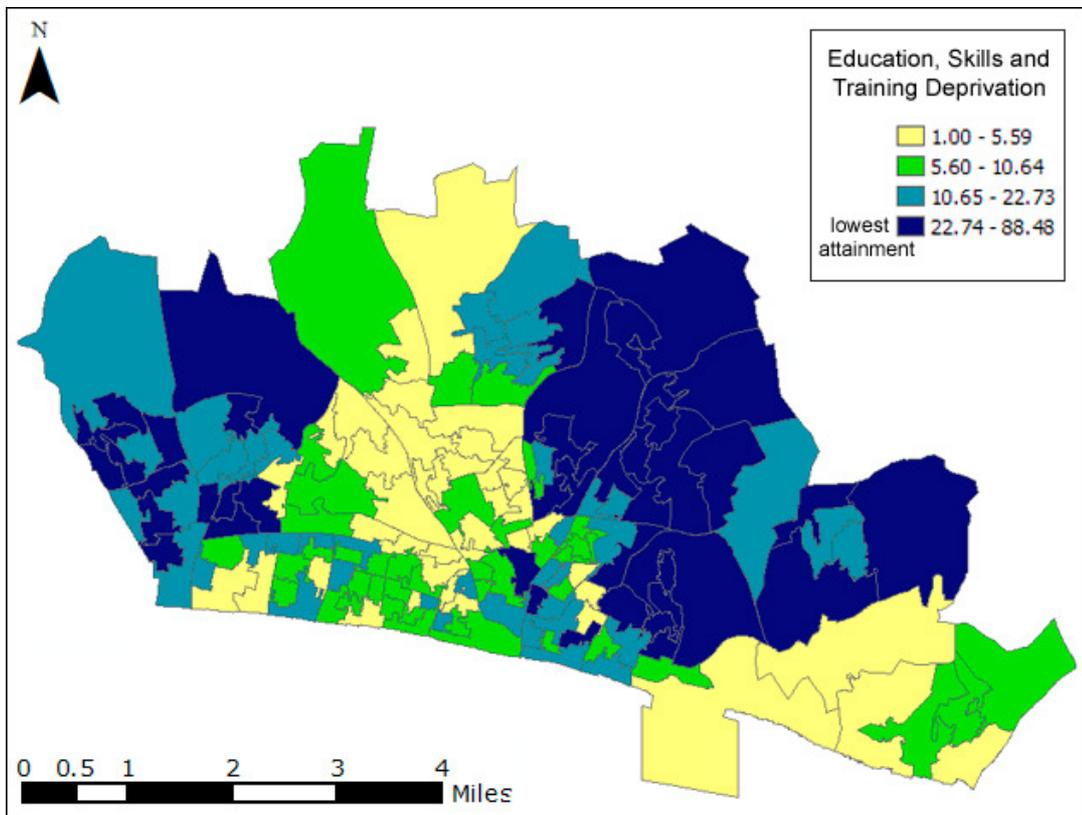
Figure 5.8: The Education, Skills and Training Deprivation Domain scores of the ID 2007
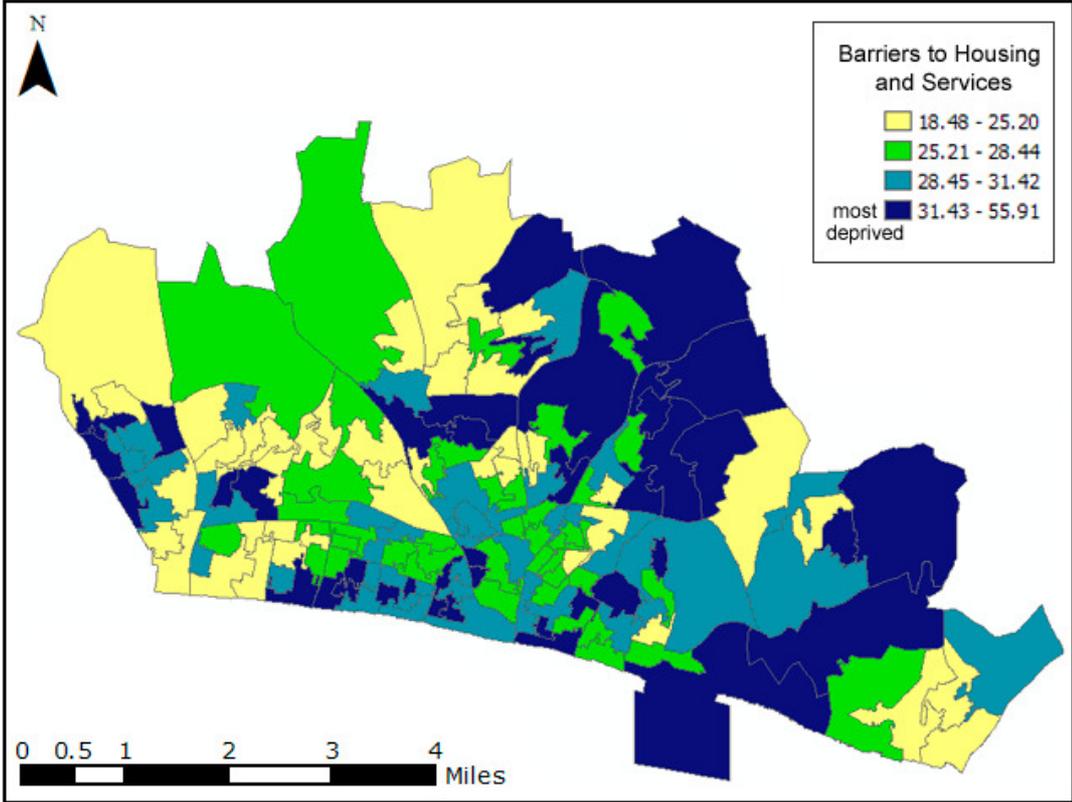
Figure 5.9: The Barriers to Housing and Services Domain scores of the ID 2007
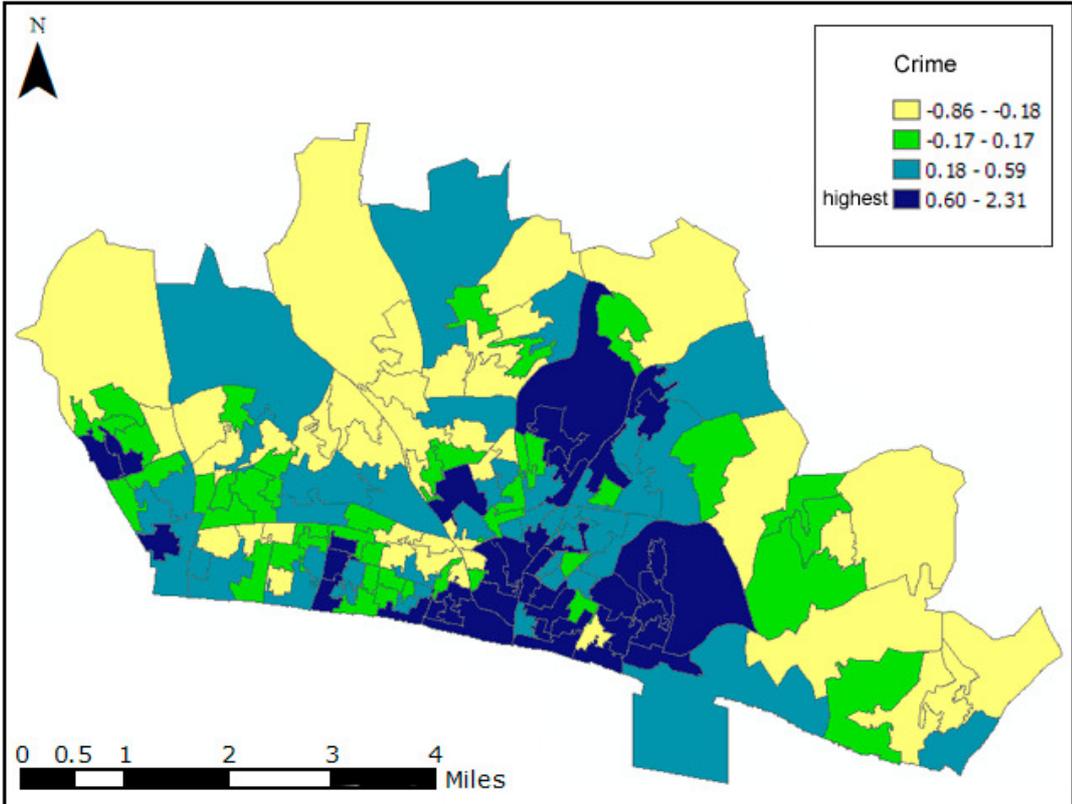
Figure 5.10: The Crime Domain scores of the ID 2007
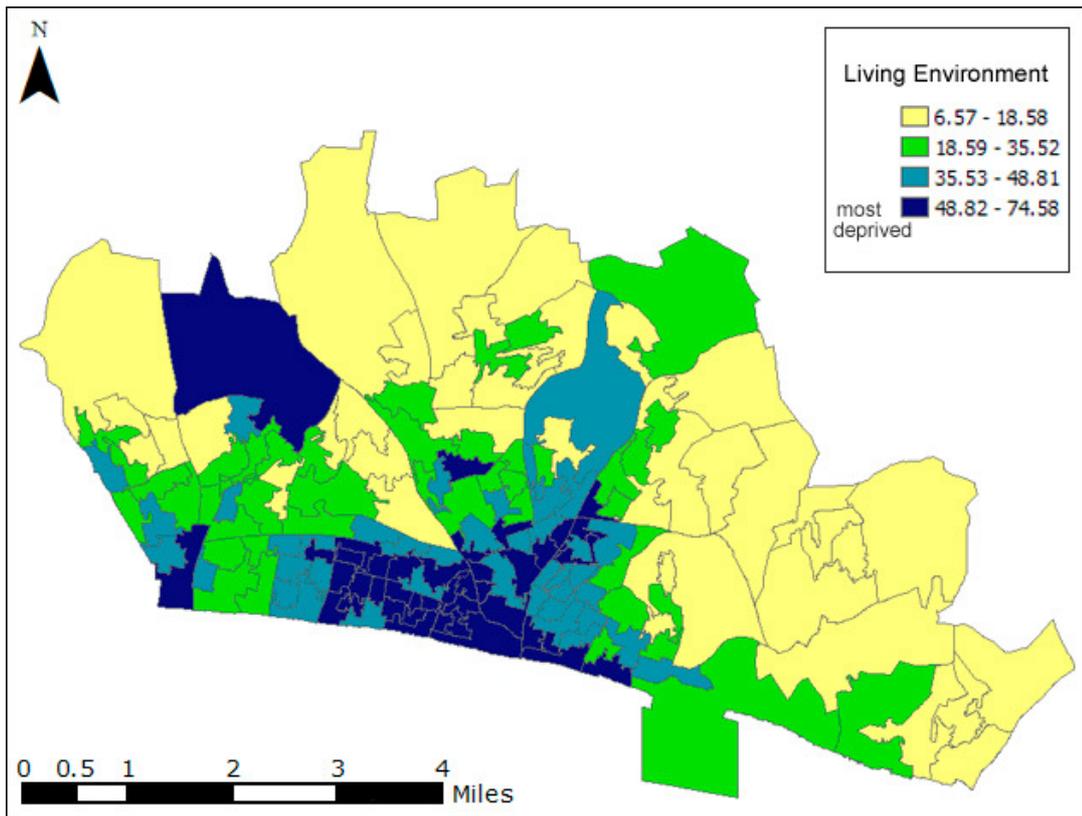
Figure 5.11: The Living Environment Deprivation Domain scores of the ID 2007
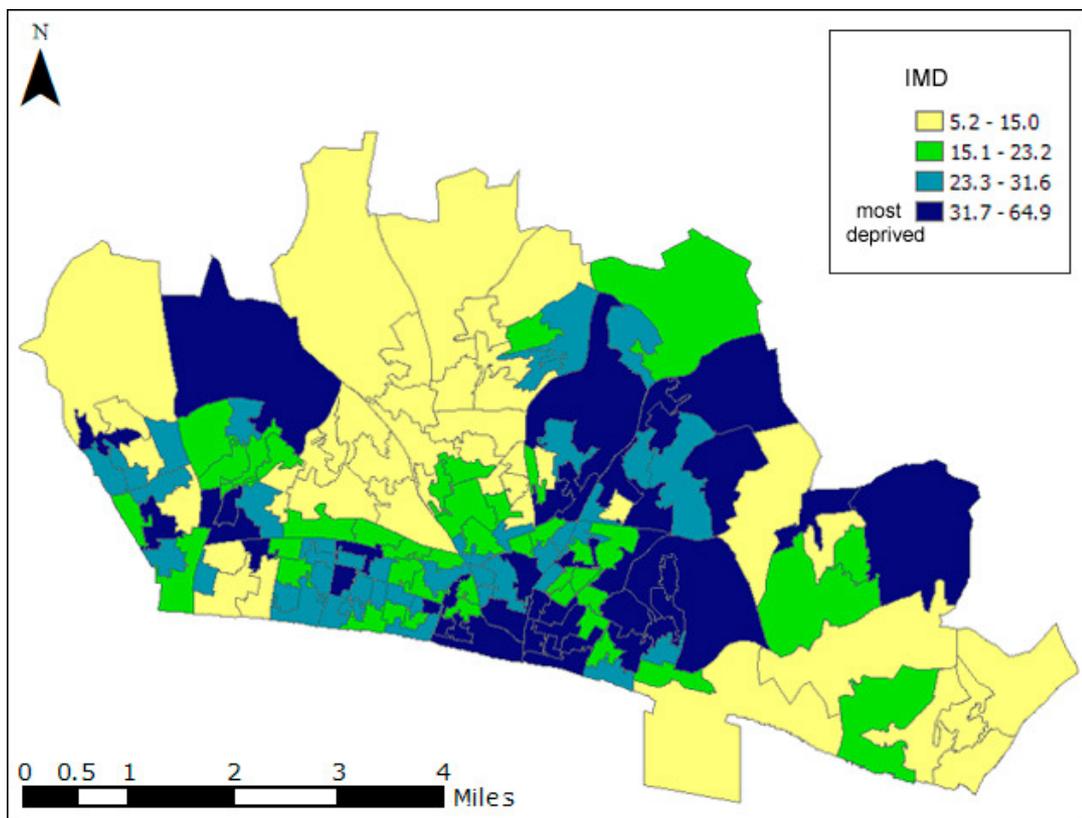
Figure 5.12: The IMD 2007 scores

The map shown in figure 5.11 is the only one in which there is no eastern tract or western region of deprivation. West of the marina, a major region of deprivation extends along the seafront and inland. A second hotspot in a contiguous area of relatively moderate deprivation extends north eastwards.

IMD scores are obtained by weighting and combining the individual domain scores. The income and employment deprivation domain scores together contribute 45% of the IMD score and the health and education deprivation domains together contribute a further 27%. That this map appears to be closely related to the income, employment and health deprivation domain maps is not therefore surprising. These three domain maps, and the IMD map, also share with the ward and SOA level maps of children and young people on the Compass, hotspots in the East Brighton and Moulsecoomb and Bevendean wards. However, other hotspots also feature in them but not in the Compass maps.

5.5 Geographical Inequalities in Income Deprivation Affecting Children in Brighton and Hove

The focus of this thesis is disabled children, many of whom live in or near the margins of poverty (discussed in Chapter 2). Low income was recognised by Townsend (1987) as a central component of multiple deprivation. However, as the child population is distinctly differently distributed within Brighton and Hove compared to working age and older people (Figure 5.3), the overall Income domain score is unlikely to adequately reflect the proportions of children living in income deprivation in each SOA.

Fortunately, two additional indices that measure income deprivation in specific age groups of the population were appended to the ID 2007 (and the ID 2004). These are the Income Deprivation Affecting Children Index (IDACI), which measures the proportion of under 16 year olds living in income deprivation, and the Income Deprivation Affecting Older People Index (IDAOPI), which measures the proportion of older people living in income deprivation.

In Figure 5.13 the SOAs in Brighton and Hove have been ranked in order of the proportions of children (top panel) or older people (bottom panel) living in income deprivation and colour-coded depending on whether they are in the least deprived (lightest shading) or increasingly more deprived quartiles of the city's SOAs.

The SOAs with the highest proportions of children living in income deprivation are in the eastern tract and in one region in the west. Whereas some of the SOAs ranking in the most deprived quartile for older people living in income deprivation also lie within these regions, they are more dispersed within the arc formed by the eastern tract, seafront region and western region. The pattern of income deprivation affecting children is more pronounced in the eastern tract and in the west, compared to income deprivation affecting older people. It is also more severe: the top quartile values range from 33% up to 74% of children affected by income deprivation, compared to 32% up to 50% of older people. Although the majority of SOAs ranking in the least deprived quartile in the city for IDACI also rank in the least deprived quartile for IDAOPI, there are a few SOAs where the rankings for the two differ by two quartiles.

As discussed in chapter 3, the Income domain of the ID 2007 records the actual proportions of people living in income deprivation in each SOA. Likewise, the IDACI records the proportions of under 16 year olds affected by income deprivation. Remarkably, the IDACI data for the 164 SOAs of Brighton and Hove reveal enormous differences in the proportions of children affected by income deprivation in different parts of the city - the scores range from 4% to 74%.

(a) The Income Deprivation Affecting Children Index (IDACI)
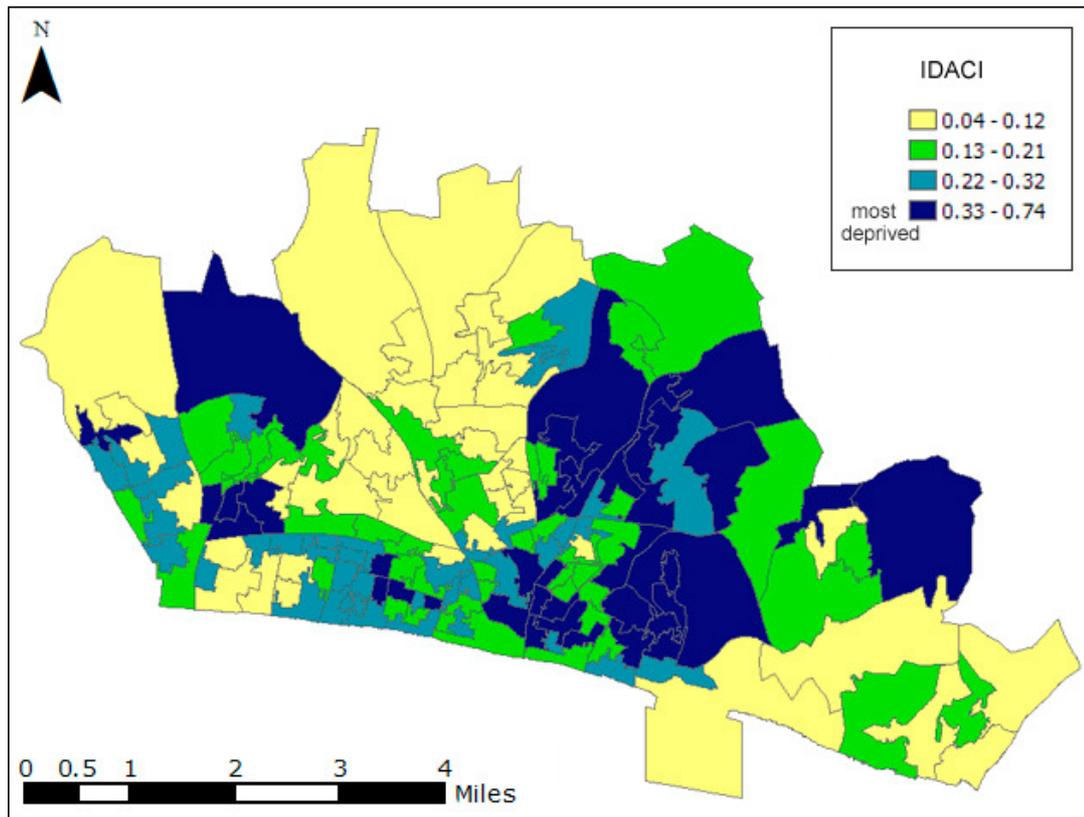
(b) The Income Deprivation Affecting Older People Index (IDAOPI)
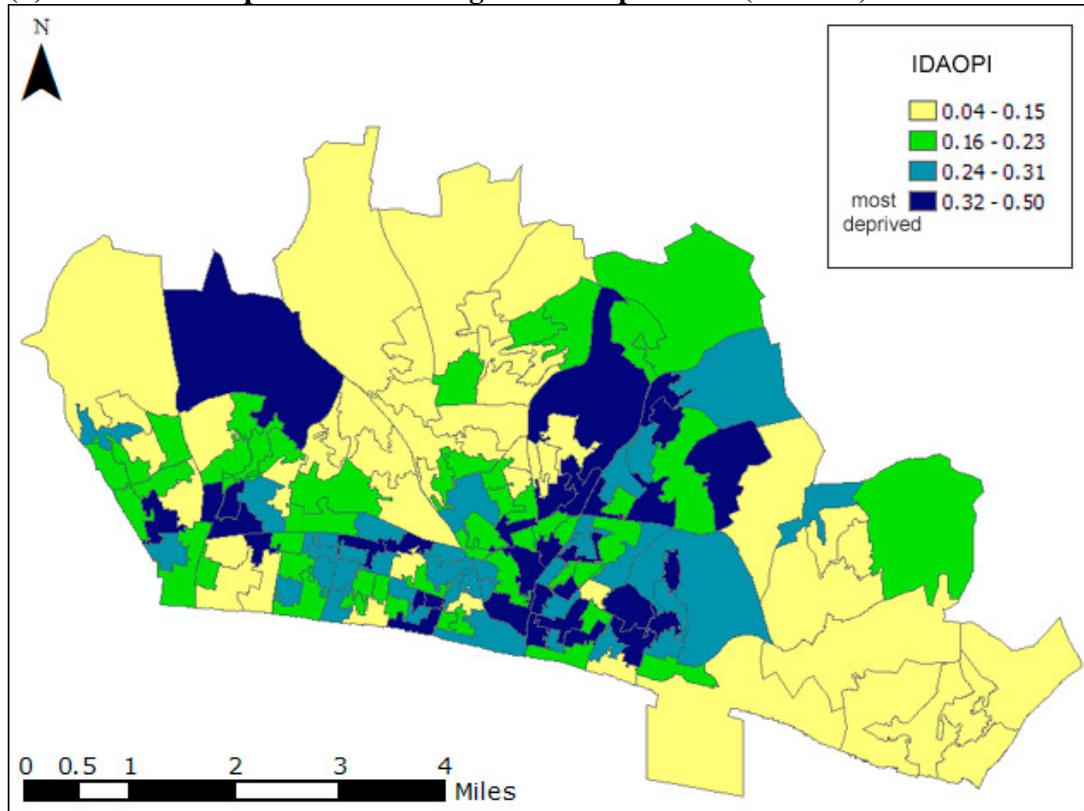
Figure 5.13: Proportions of children and older people living in income deprivation

21% (34 of the 164) SOAs in Brighton and Hove, rank within the most deprived quintile of SOAs in England for income deprivation affecting under 16 year olds. In contrast only 4% (7 of the 164) of the city's SOAs, rank within the least deprived quintile. These SOAs are shown in Figure 5.14.
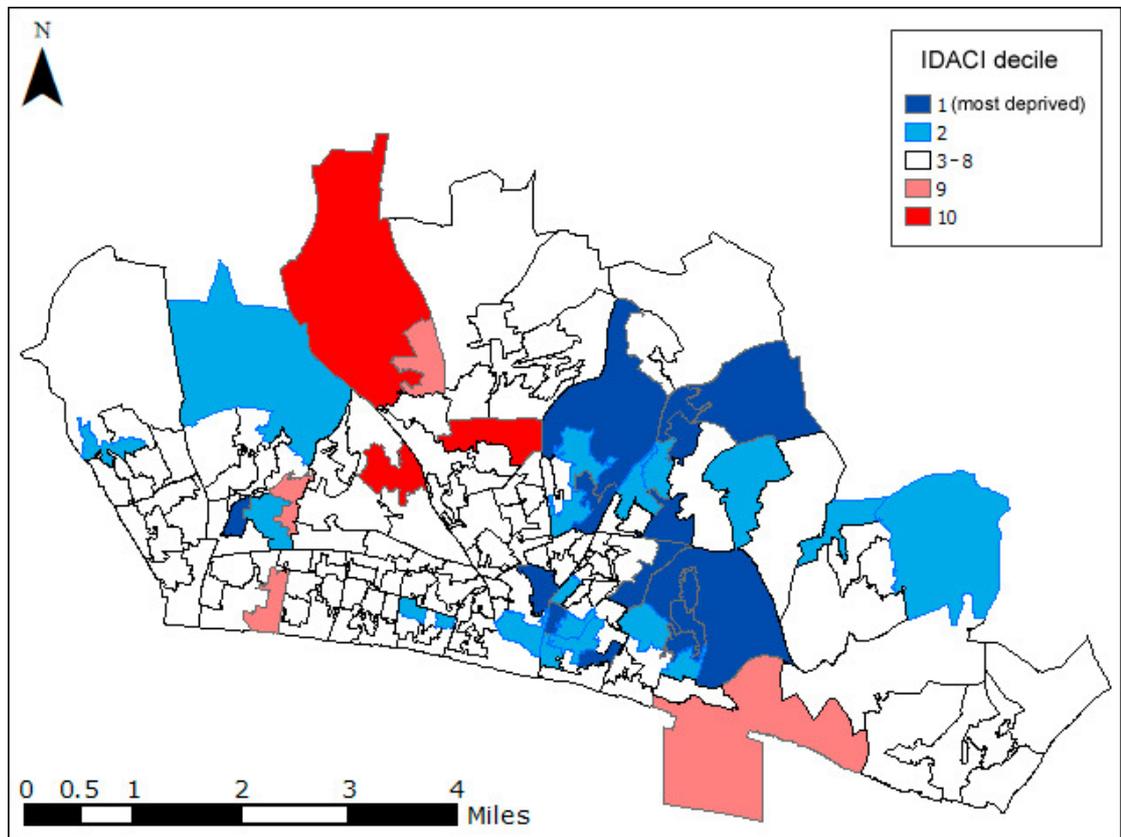
Figure 5.14: SOAs of Brighton and Hove ranking in the most and least deprived IDACI quintiles in England

SOAs ranking in the two most deprived deciles are shaded blue and those in the two least deprived deciles are shaded pink

15 SOAs - one in the west and the rest in the east of the city - rank in the most deprived 10% of English SOAs. Many of the remaining 19 making up the rest of those in the most deprived quintile (shaded light blue in Figure 5.14) are adjacent to the SOAs in the most deprived decile.

The eastern tract of the city, which contains all but one of the SOAs ranking in the most deprived decile of English SOAs for IDACI, is the subject of Figure 5.15. In this map, the SOAs where more than 50% of children live in income deprivation have been highlighted.

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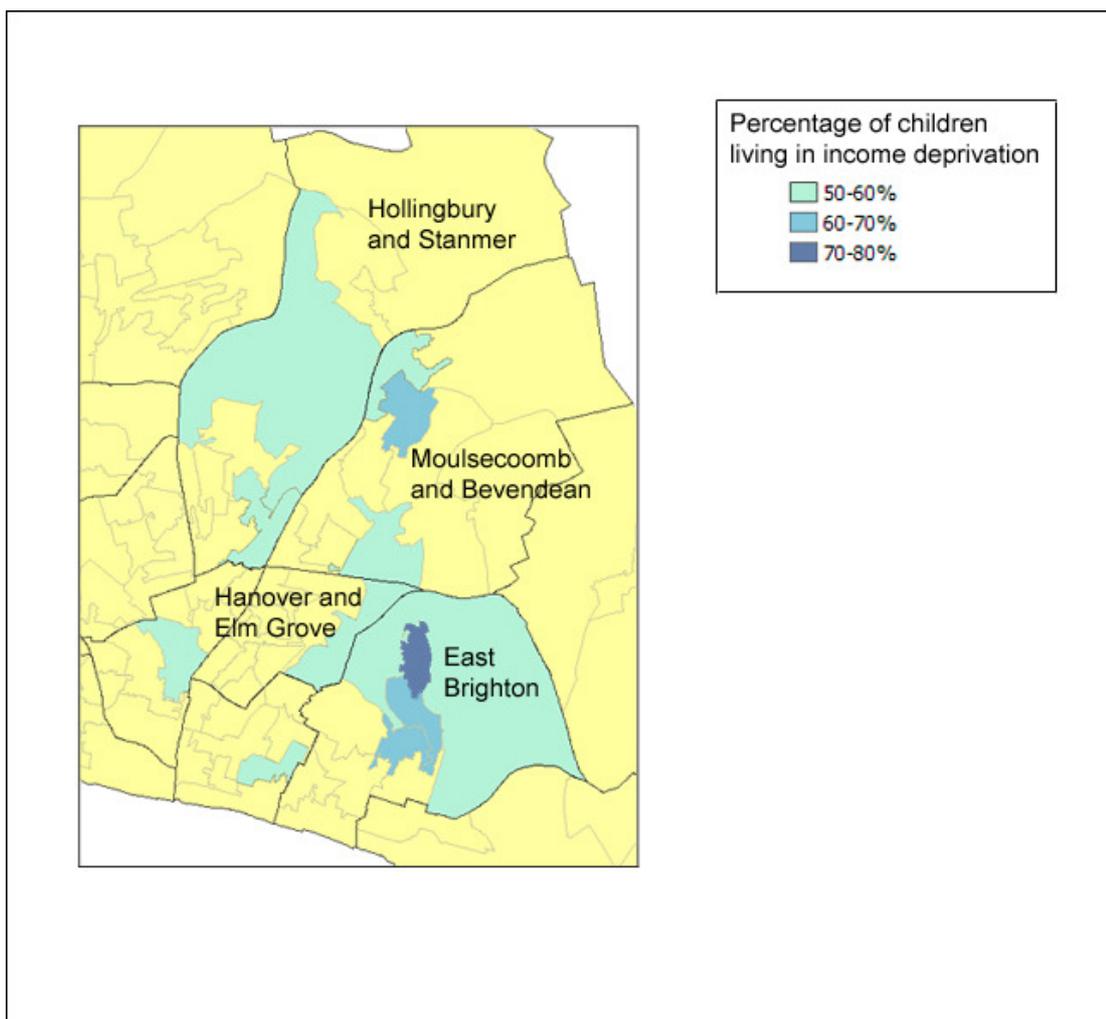
Figure 5.15: Income deprivation affecting children in the east of Brighton

SOAs where more than 50% of children live in income deprivation are highlighted and ward boundaries are shown.

Ward boundaries are included to help the reader pinpoint the location of the SOAs in the eastern tract of the city where more than half the children live in income deprivation. The SOAs where more than 50% of children are affected by income deprivation form two main regions. One extends from the northern half of the East Brighton ward through an eastern portion of Hanover and Elm Grove ward and into Moulsecoomb and Bevendean ward. The other includes parts of Moulsecoomb and Bevendean ward and Hollingbury and Stanmer ward. Previously, the three SOAs with the highest numbers of children on the Compass were identified (Figure 4.4). These correspond to three of the four SOAs with 60% or more of its under 16 year olds affected by income deprivation.

The finding that children living in different areas of the city experience dramatically different levels of income deprivation should be of pivotal importance to service providers and planners. Professionals need to reflect on how this may affect:

- how, and whether, families access services,
- how, and whether, they present to services,
- how, and whether, they take up what is on offer for their children.

However, when it comes to resourcing services for individual children, it is important to know about the numbers of children living in deprivation in an area, not just the proportions.

In Figure 5.16 the numbers of children estimated to be living in income deprivation in each SOA of Brighton and Hove are mapped. These numbers were calculated by multiplying together:

- the IDACI scores (from ID 2007), which record the proportion of under 16 year olds living in income deprivation in each SOA, and
- the numbers of under 16 year olds in each SOA (from the ONS mid-2005 population estimates).

As the numbers of children estimated to be living in income deprivation are so uneven, in the main part of Figure 5.16 the stepwise distribution of numbers per SOA is shown rather than interquartile rankings. However in the inset panel, SOAs with numbers ranking in the top quartile of the range of values are highlighted.

In most SOAs fewer than 50 children are estimated to be living in income deprivation, but eight SOAs in the eastern tract are estimated to have over 200 children living in income deprivation. The four that are in the top quartile of values are highlighted in the inset panel of Figure 5.16. The values range from 256 to 337. The two major foci for high numbers of income deprived children that they define map in the East Brighton and Moulsecoomb and Bevendean wards.
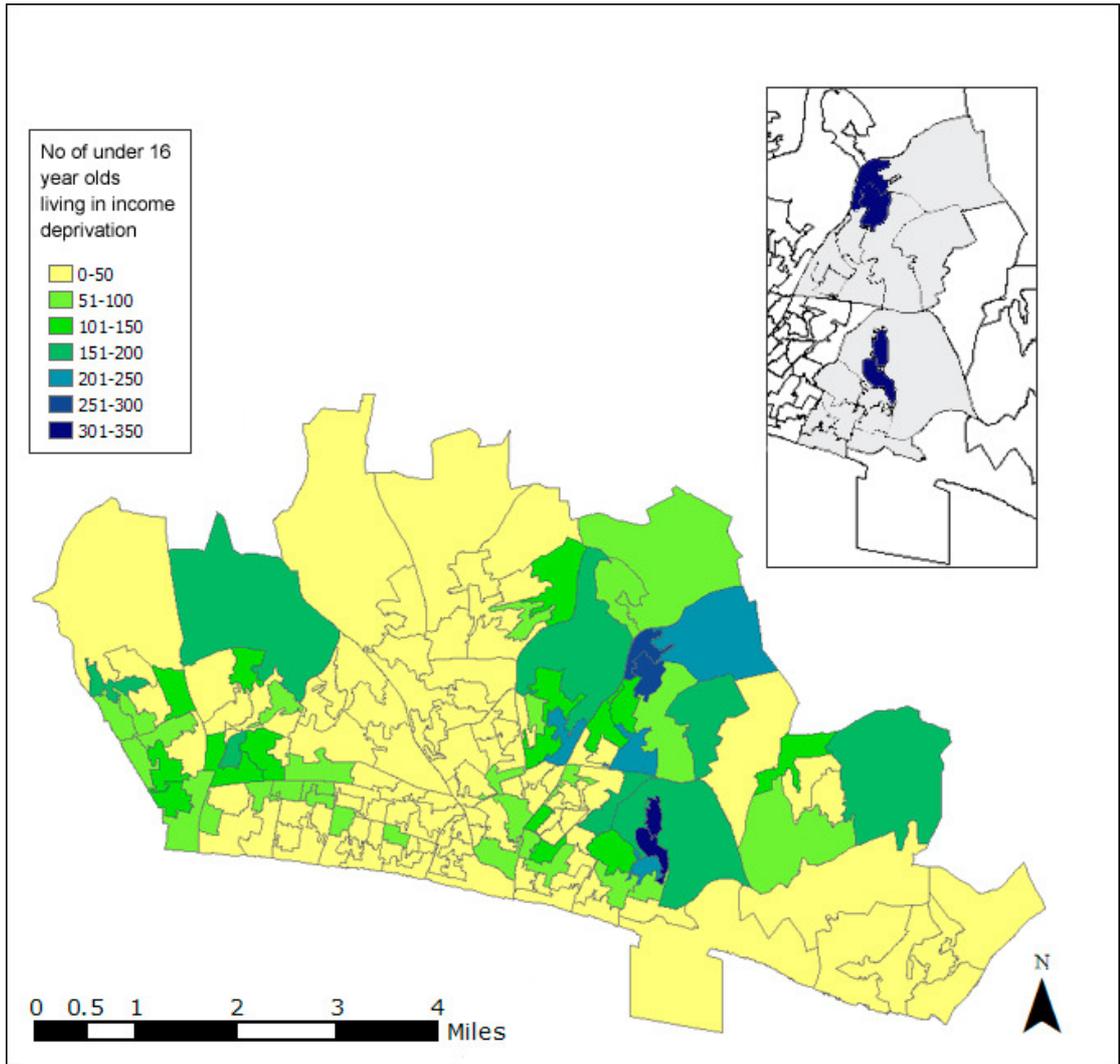
Figure 5.16: Numbers of under 16 year olds living in income deprivation in Brighton and Hove

The inset panel shows the four SOAs that are in the top quartile of values. Other SOAs in the East Brighton ward and Moulsecoomb and Bevendean wards are shaded yellow.

A comparison of the map in Figure 5.16 and that showing where under 16 year olds on the Compass live (Figure 4.4) reveals remarkable overall similarities, especially in the eastern tract of the city. Moreover, three of the four SOAs that are in the top quartile of values for under 16 year olds living in income deprivation also make up the top quartile of values for under 16 year olds on the Compass.

The estimates from these data are that of the 40,728 under16s in the city:

- 10,116 – a quarter of them - live in SOAs that rank in the most deprived quintile in England for income deprivation affecting children.
- 4.6% of them live in the seven SOAs that rank in the least deprived quintile.

But of the 10,263 under 16s in the city living in income deprivation:

- 5,082 – nearly half of them - live in the SOAs that rank in the most deprived quintile.
- In contrast, only 0.8% of them live in the seven SOAs that rank in the least deprived quintile.

How accurately this data summary and the map (Figure 5.16) reflects the current reality of income deprivation affecting children depends on: how good the IDACI is at measuring income deprivation affecting children and on how the situation has changed since the data used to construct it were collected, as well as the accuracy of the population estimates. Even admitting some inaccuracy, this analysis suggests that children living in income deprivation are highly spatially polarised within the city.

In the map in Figure 5.17 the Moulsecoomb, Bates, Saunders Park and Whitehawk housing estates in the east of Brighton are highlighted. Moulsecoomb, the largest estate in Brighton, was established in the 1920s and Whitehawk soon after, in the 1930s. The houses were spacious and located close to the downs, but both estates soon became foci for deprivation. The reasons for this are still a matter of debate, but it is likely that their residents experienced greater social isolation than those of other estates in the city (such as the Knoll estate in Hove). Duncan and Edwards (1999), in their study on the material contexts and social capital of lone mothers in different neighbourhoods, describe Moulsecoomb as a typical peripheral housing neighbourhood, residualised and associated with social problems, built originally as a public housing answer to the central town slums, but with the nicest houses now sold off into owner-occupation.

Located in two of Brighton's valleys, both Moulsecoomb and Whitehawk estates are physically separated from, and have few natural links to, the rest of the city, and both contain relatively few shops and meeting places. A comparison of the location of these housing estates with Figures 5.16 and 4.4 reveals that the SOAs with the greatest numbers and concentrations of under 16 year olds living in income deprivation, and under 16 year olds on the Compass, are coincident with areas within the Moulsecoomb and Whitehawk estates.

Figure 5.17: Housing estates in the east of Brighton

5.6 Different socio-economic groupings of families in Brighton and Hove?

The technique of cluster analysis is widely used in human geography. For example, see: Ruger and Kim (2006), Shelton *et al.* (2006), Dorling *et al.* (2007), Gutman and Brown (2008). The ONS's 2008 Area Classification of Super Output areas and Data zones, which groups together geographic areas according to key characteristics common to the population, is derived from cluster analysis of 2001 census data. An interactive map is available at http://www.spatial-literacy.org/ONSMap/ and the map area that includes Brighton and Hove is shown in Figure 5.18
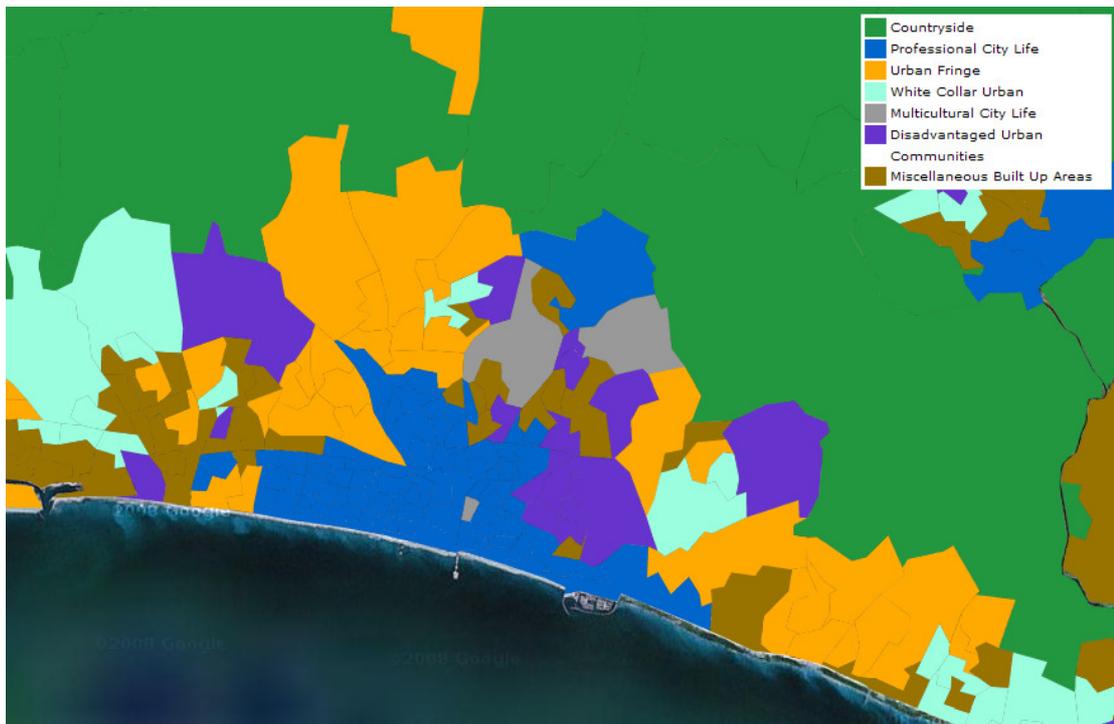
Figure 5.18: The ONS classification of SOAs in the vicinity of Brighton and Hove

Here cluster analysis of 2001 census variables has been used to describe the whole population. The purple shaded SOAs represent those with 'Disadvantaged Urban Communities'. However, although this classification is extremely useful, it is a generalised one, with for example, no focus on children and young people.

It might be possible to use cluster analysis of 2001 census data to provide a more child-centred classification of socio-economic groups within Brighton and Hove. Although few census variables relate directly to families with dependent children, others relate to working age people, many of whom are parents, and more can be created by uncoupling data on students and on older people. Variables were chosen or constructed and data was collated for the MSOAs of Brighton and Hove. These variables described:

- the proportions of working age people
    - in different skill-levels of employment
    - with different levels of educational attainment
    - who are unemployed
    - who are sick or disabled
- the proportions of households that are
    - single parent families with dependent children
    - have no adults in employment and dependent children
    - single parent families with dependent children and no adults in employment
    - owner occupiers

Related three or four or five cluster models were derived using Ward's method for cluster analysis and different subsets of the variables. The resultant dendrogram for the (nominally) four cluster model is shown in Figure 5.19(a).

According to the dendrogram, the cluster comprising MSOAs 8, 9, 25 and 2 is the most dissimilar from the other three clusters. This corresponds to cluster 2 (shown in blue) in panel (b). The next most dissimilar is the cluster comprising MSOAs 6, 12, 13, 17, 5, 1, 21, 16 and 18. This corresponds to cluster 1 (shown in red) in panel (b). The third cluster comprises MSOAs 10, 11, 3, 33, 4, and 7. This corresponds to cluster 3 (shown in green) in panel (b). The remaining MSOAs make up the fourth cluster, which is most closely related to the third cluster, and this is depicted in purple in panel (b).

(a) Dendrogram using Ward's method

Rescaled Distance Cluster Combine
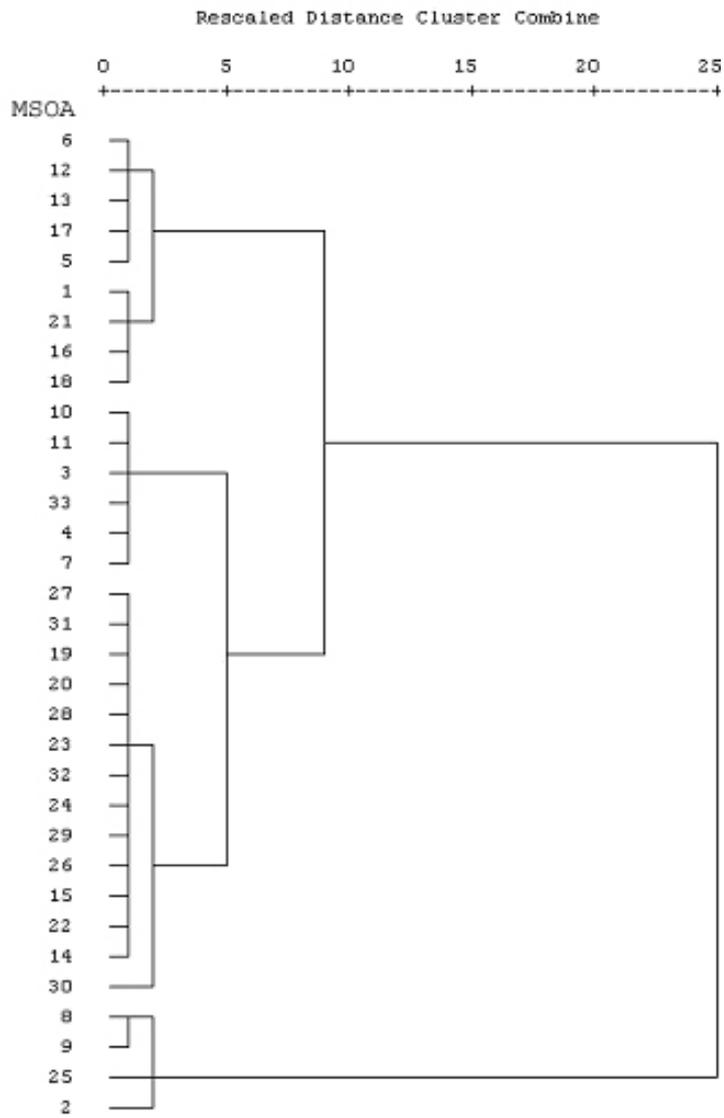
(b) Cluster characteristics
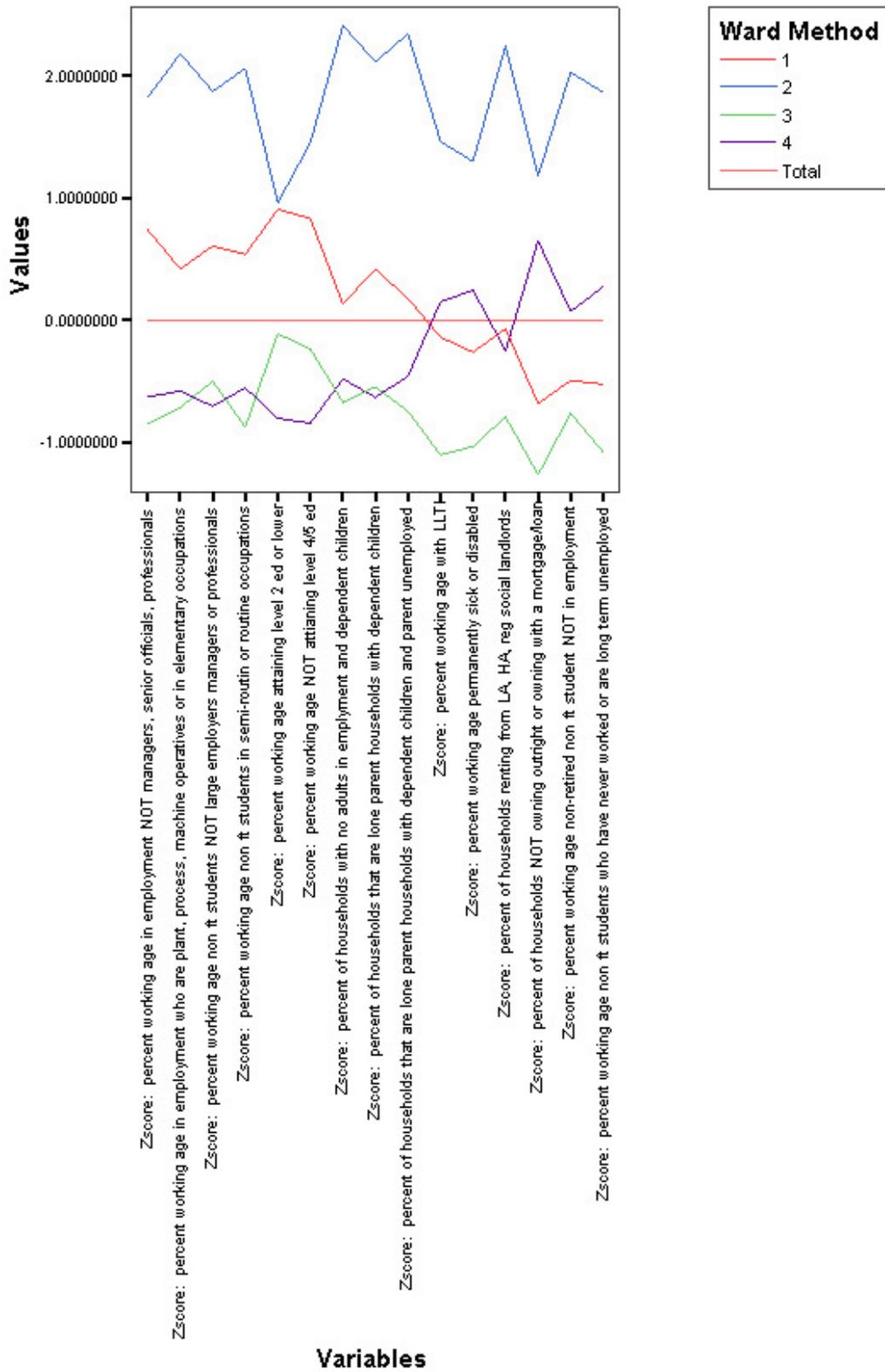
Figure 5.19: Cluster analysis of working-aged people and families with dependent children

In Figure 5.20 the four clusters are mapped. The same colour coding is used as in Figure 5.19(b). The numbering of MSOAs in Brighton and Hove is included for reference.
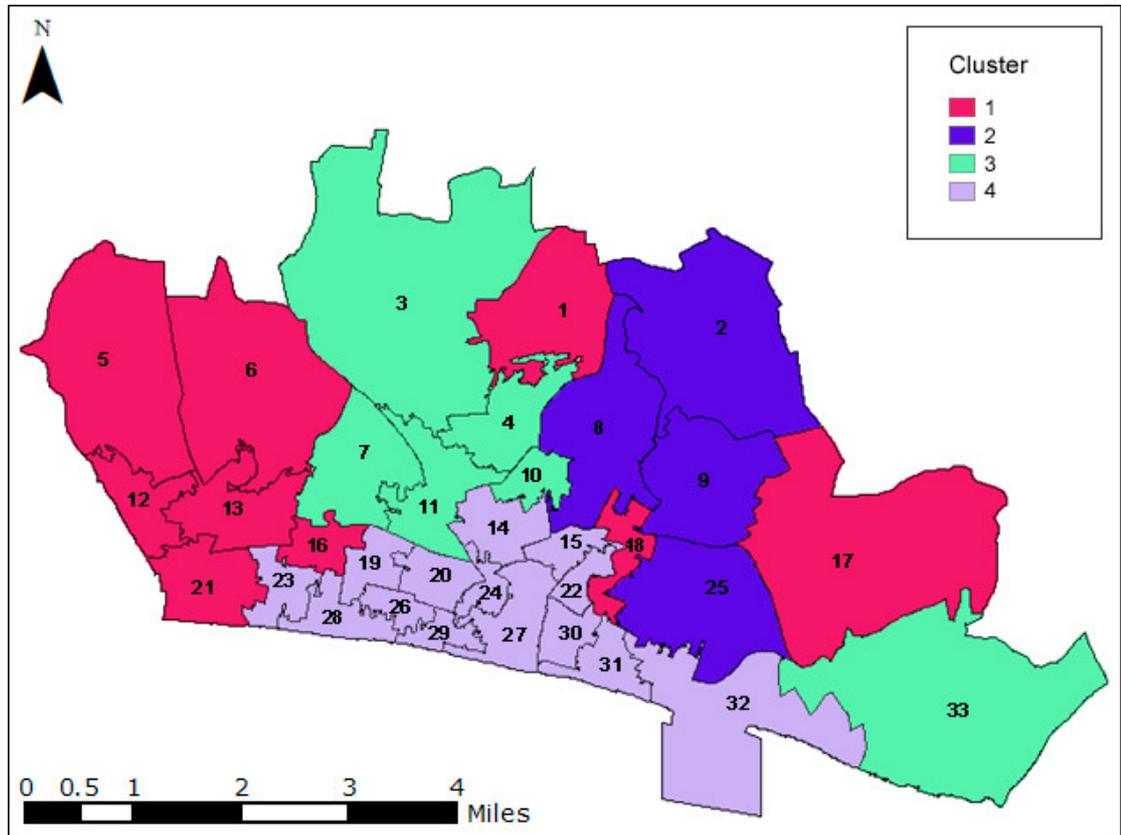
Figure 5.20: Distribution of the four clusters of working age people and families with dependent children

Importantly, two of the four derived clusters (cluster 2 shown in blue and cluster 4 shown in purple) define single geographic areas (made up of contiguous SOAs), and the other two clusters each define a single geographic area comprising five or more contiguous SOAs, as well as one or a few additional discrete areas. The matching of each cluster to one or a few discrete geographical areas supports the possibility that the exploratory technique may have produced a meaningful result. According to Figure 4.12(b), the cluster shown in blue represents a socio-economic grouping of working age adults and families that is most different to the other groupings in having markedly higher levels/proportions of:

- unemployment, including families with dependent children where no adults are in employment,
- single parent families and
- working age adults reporting 'long-term limiting illness' (see chapter 5 for a full discussion of 'long-term limiting illness').

Overall, educational attainment is also lowest in this group but the difference is less pronounced than for the other variables.

5.7 Conclusions

In this chapter the distribution of broad age groups of the population of Brighton and Hove was described, focusing on children (under 16 year olds), in the context of deprivation.

McKendrick (2001) noted that in contemporary population geography children are often treated as objects rather than the subjects of the research. Results presented in this chapter highlight that the SOA geography is of limited or qualified relevance to studies on children. SOAs were designed to have similar total numbers of inhabitants, but (unless the proportions of older people and children and young people are the same in each SOA) the numbers of children (and older people) will be more variable than the total number of inhabitants.

The observation that SOAs contain much more variable numbers of children than total inhabitants is, arguably, self-evident, making the analyses presented in Figure 5.4 redundant. However this fact is unlikely to be obvious to non-geographers, including many planners of children's services. Even if the total population is the subject of study, it is important to appreciate the 'flexibility' in the population size of SOAs and to recognise that variation in the numbers of inhabitants in different SOAs is likely to increase over time.

Similarly, the ONS's 2008 Area Classification of Super Output areas and Data Zones does not provide information directly relevant to children or older people; it relies on key census tables that do not contain information specifically about children.

In this chapter the numbers and proportions of under 16 year olds living in each SOA, and the numbers and proportions of them living in income deprivation, were estimated. The mapping also showed that hotspots corresponded to core areas of the Moulsecoomb and Whitehawk council estates.

It would probably be very valuable for planners of children's services in any local authority to undertake similar analyses. Those planning universal children's services need to know about the numbers of children in their different service delivery 'patches', and, in many cases, they will want to preferentially promote their services to the most deprived children.

Spicker (2001) has argued that there are 'poor areas', not just poor individuals, and that the features of poor areas make the residents more vulnerable to becoming caught and enmeshed in the poverty web. Areas where many of the residents are poor are perceived as 'bad' areas, and consequently people of higher economic status choose not to live there. Perversely, because more people are poor, there are fewer resources and facilities, such as shops and post offices, leisure centres and child care provision, than in the more middle class areas, where people tend to have fewer needs. An area's bad reputation may mean that residents cannot get credit, have to pay higher insurance premiums, and cannot get shopping delivered or access taxi services. Poorly built or designed social housing has also been posited to contribute directly to social problems.

Therefore it is also important for service providers to understand which neighbourhoods have high or low proportions of children living in income deprivation, as the ways families access services, and the kinds of barriers they encounter to receiving services, may be very different in more and less deprived areas.

The analysis presented here has shown that in Brighton and Hove there is a remarkable coincidence between the SOAs in which high numbers of children are affected by income deprivation and in which there are high numbers of disabled children.

It would be fascinating to generate a children's geography for England by mapping the numbers and proportions of children per SOA. This could be extended to produce a children's deprivation (or even disability) map, perhaps in the style of 'Worldmapper' (www.worldmapper.org), where territories are re-sized according to the subject of interest. Such maps could aid local planning of children's services. Indeed, Paul Bivand and Sean Moley of the Centre for Economic and Social Inclusion and Donald Hirsch, independent consultant for End Child Poverty, have recently provided an online map of levels of child poverty in each local authority. Maps for each region can be viewed at http://www.endchildpoverty.org.uk/why-end-child-poverty/poverty-in-your-area. Ward level data is included on the numbers and percentages of children in workless families, low income families and families on Working Tax Credit.

The data presented here illustrate the extreme polarisation children experience in Brighton and Hove with respect to income deprivation. It is striking, if unsurprising (based on Brighton and Hove's recent history), to find that the hotspots for this deprivation map within the Whitehawk estate and the Moulsecoomb estate. The cluster analysis presented in Section 5.6 is in keeping with these findings in that it suggests that a quite discrete group of socio-economically very disadvantaged families with disabled children live in the east of Brighton and another somewhat less disadvantaged group live in the west.

The work of Dorling and Rees (2003) suggested that the spatial separation between different social groups in Britain, that had grown rapidly during the late 1980s to late 1990s, under a Conservative government, was still increasing almost as rapidly at the turn of the century. Although their work confirmed that families were overall better off than a decade ago (for example, the proportions of households with no sole bathroom or no central heating were lower), the poorest households were becoming increasingly spatially marginalised. They

suggested that this was because people who could choose where to live were choosing to live further away from people who could not and they concluded (2003: 1301) that: "To be growing up in a council house now marks a household out geographically far more than it did a decade ago".

Garner (2009) provides a somewhat different perspective. He describes how the nature of social housing has changed since the 'right-to-buy' legislation of the early 1980s. The ensuing major rise in the levels of home ownership, together with the more recent transfer of housing stock from local authorities to housing associations, resulted in a decline in the proportion of households renting homes from the council from 34% in 1981 to only 14% by 2002. With demand outstripping supply, working-class families on low to medium wages, who used to be relatively certain of accessing council housing, are now unlikely to do so; and it is largely only people who are technically homeless, and/or have multiple social problems, disabilities, or dependent children, who are housed by local authorities in the short to medium term. By 2002 the average income of owner-occupancy households was 2.8 times that of social housing households. One out of every two lone-parent families lived in social housing compared to one in seven of other family structures. More than three-fifths (63%) of social housing renters were economically inactive compared to less than one third (31%) of owners. Thus Garner (2009: 46) concludes that social housing has now become: "a last-gasp resource for the residual very-low income and benefit-receiving section of the working class".

Thus, the allocation of the small amount of housing stock available to very disadvantaged families could actively contribute to creating and maintaining deprivation foci in Whitehawk and Moulsecoomb.

Further insights into the societal context come from studies such as that of Blanden *et al*. (2005) on social mobility in Britain. These authors compared the economic outcomes for pairs of men in their early 30s, one born to parents earning twice as much as the other. Whereas in the early years of this century the ones from the richer families would be earning 25% more than the those from the poorer families, a decade earlier the differential was only 17.5%. They also

calculated that the proportion of young people from the richest families who got degrees in the late 90s (46%) had more than doubled compared to the early 80s, whereas the proportions of those from the poorest families (9%) had hardly changed. Blanden *et al*. (2005: 18) concluded that: "Children born to poor families are now less likely to break free of their background and fulfil their potential than they were in the past".

The extent to which disabled children and their families experience deprivation has not been fully characterised, and the link between childhood disability and deprivation remains relatively unacknowledged and unexplored by children's geographers. Just as small area level analysis is crucial for understanding the extreme polarisation in the numbers of disabled children within locales, it is equally important in determining the magnitude of the deprivation some disabled children experience. In short, without the micro-geographical perspective the deprivation differences are likely to be obscured. Therefore in the following chapter the extent of deprivation experienced by children on the Compass living in different areas of the city is explored.

Chapter 6

The Connections between Childhood Disability, Place of Residence and Disadvantage

Introduction

As the Compass collects information on a variety of factors relating to each child's circumstances, including their housing, schooling, and health, there is scope to deconstruct the broad (average) picture and to investigate how disabled children's life circumstances differ in different areas within the city. In this chapter the circumstances of children and young people on the Compass residing in SOAs with different levels of income deprivation affecting children are examined, using information provided at Compass registration. Data on all children and young people who were registered on the Compass in Spring 2008 is analysed. In the first section children living in SOAs in the East Brighton housing estates were found to be on the Compass as those living in the city's least deprived areas. Next, more significant proportions of children living in the deprived Eastern tract of the city were shown to be more likely to experience each of a range of disadvantages than those living in less deprived areas. Intriguingly, higher proportions of them were also reported to have ADHD and lower proportions to have ASCs than in the less deprived areas. In the next section it was demonstrated that some children on the Compass experience multiple deprivation and that those living in the more deprived areas of the city are at greater risk. Finally, the remarkable disparities in the proportions of disabled children, and their life circumstances, in the Eastern tract of the city compared with less deprived areas are discussed.

6.1 The numbers and proportions of children on the Compass living in the most and least income-deprived quintiles of the English SOAs

To provide some geographic context for the analyses presented here, Figure 6.1 shows the SOAs of Brighton and Hove that rank within the two most and least deprived quintiles of the English SOAs for income deprivation affecting children (IDACI). And in Figure 6.2 the SOAs ranking in the two most deprived five percentiles of English SOAs are shown.

The maps shown in Figure 6.1 illustrate that Brighton and Hove is a city divided into highs and lows of income deprivation affecting children - with a deprived western region and a very deprived eastern tract flanked by much less deprived central inland and south eastern regions. Brighton and Hove City Council (2005) has produced a ward-level socio-economic profile of the city, covering demographics, the labour market and the economy, and poverty and economic inactivity. The three constituent reports provide an analysis of 2001 census data and data from the Indices of Deprivation published in 2004. Although they do not include any maps, do not specifically consider income deprivation or disability affecting children, and include only limited SOA-level analysis, the 'cheek by jowl' nature of deprivation and affluence in the city is noted. And the area-based initiatives, aimed at narrowing the gap between the most and least deprived residents – Neighbourhood Renewal, EB4U (the New Deal for Communities in East Brighton) and Sure Start - are listed.

Figure 6.2, focuses on SOAs in the most deprived decile and SOAs ranking in the most deprived five percent of English SOAs are distinguished from those ranking in the next five percentile. A comparison with Figure 5.17 shows that the SOAs ranking in the most deprived five percentile closely correspond to the two areas making up the housing estates in the east of Brighton. Most other SOAs ranking in the top decile are in or adjacent to these estates. There is just one that is in the west and three more that are in the east but closer to the city centre.

(a) SOAs ranking in the two most deprived quintiles
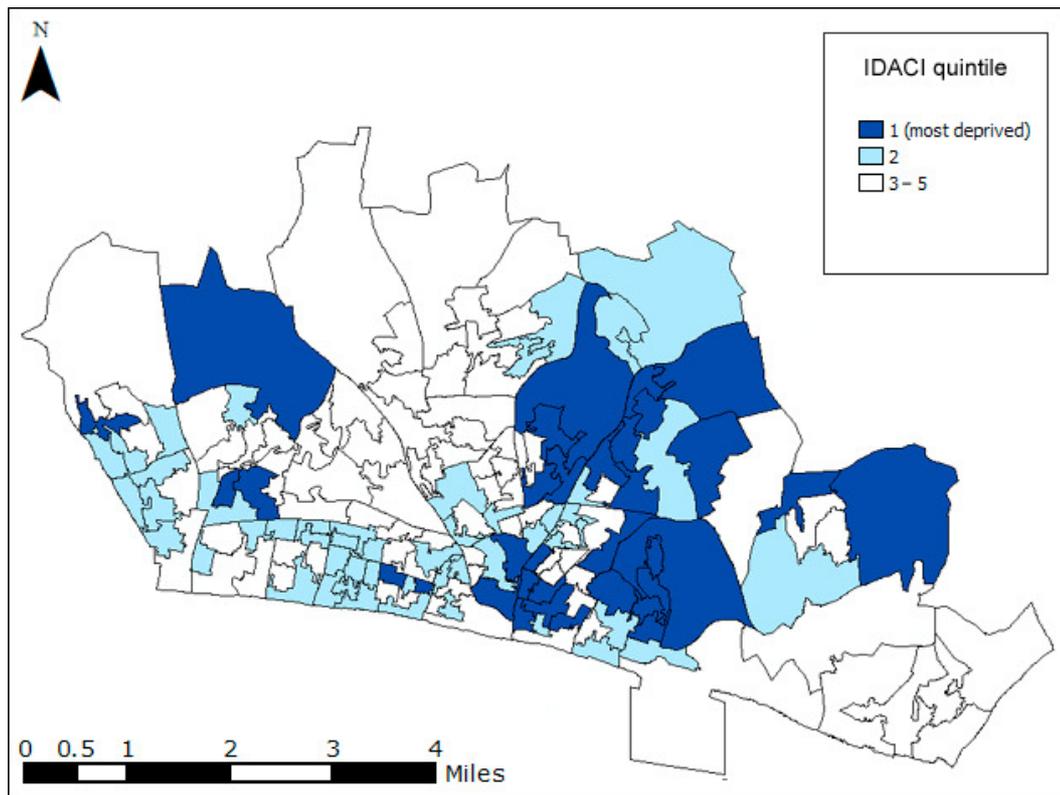
(b) SOAs ranking in the two least deprived quintiles
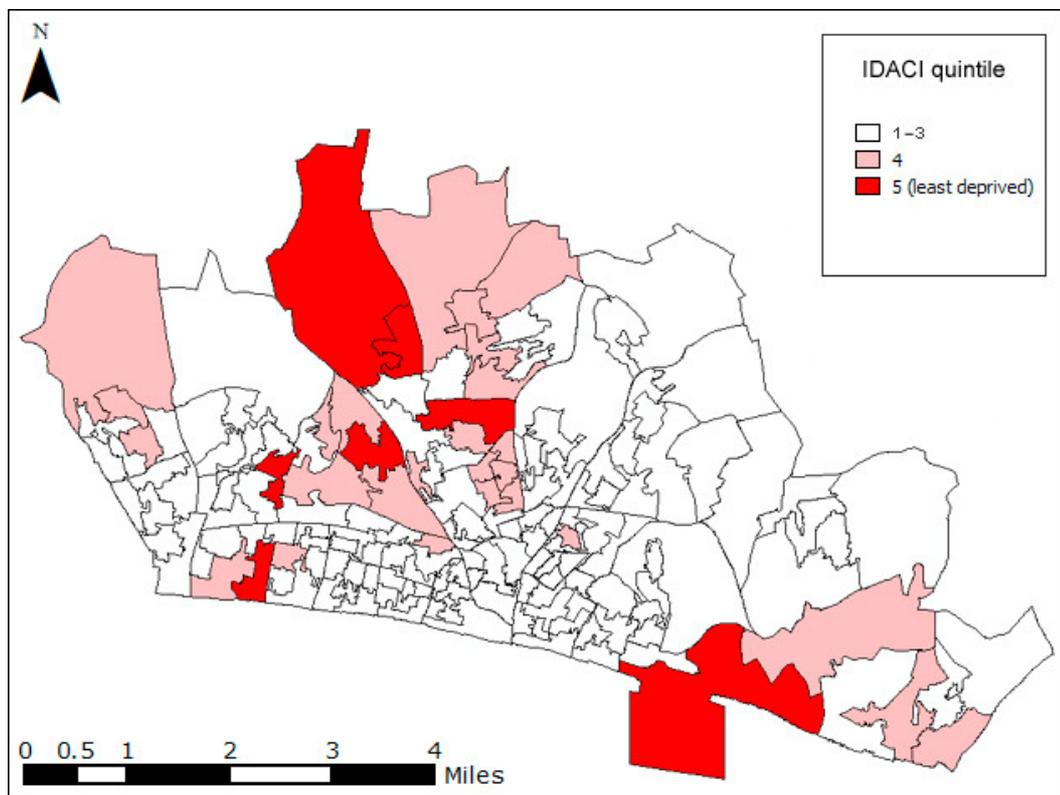
Figure 6.1: SOAs of Brighton and Hove ranking in two most and least deprived national quintiles for IDACI
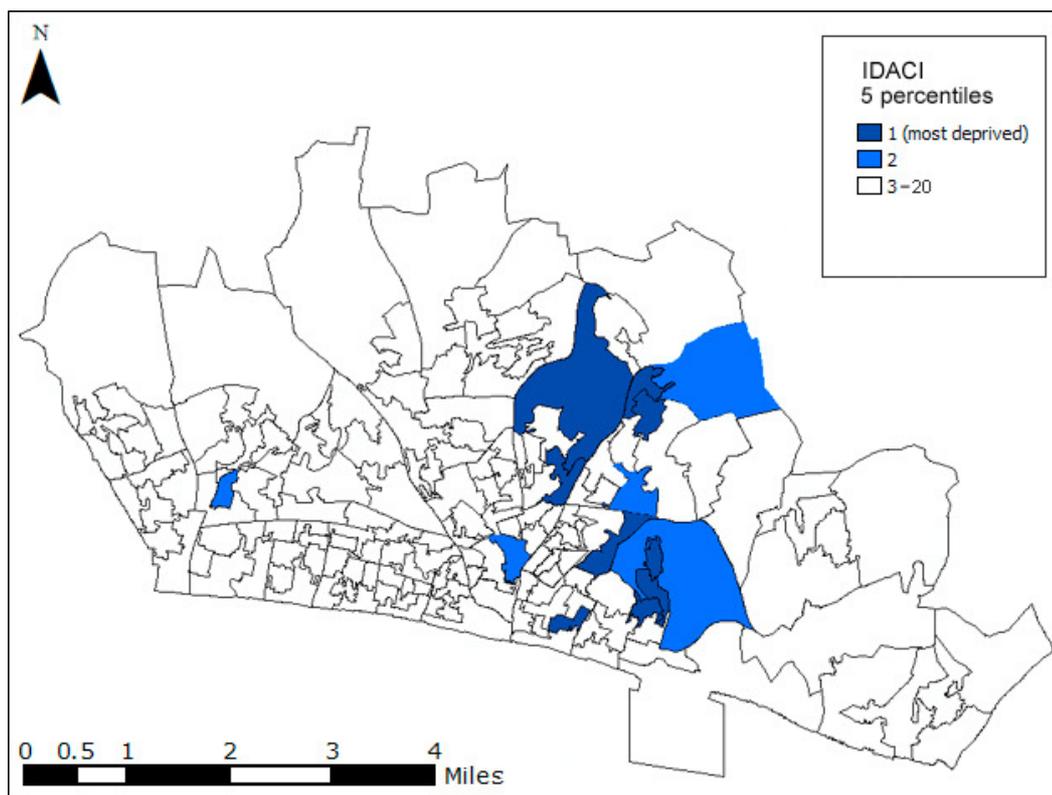
Figure 6.2: SOAs of Brighton and Hove ranking in the most deprived national decile for IDACI

The numbers of under 16 year olds on the Compass in SOAs ranking in each quintile were:

- Quintile 1 (the most deprived quintile):   354
- Quintile 2:   187
- Quintile 3:   144
- Quintile 4:   84
- Quintile 5 (the least deprived quintile):   20

In Table 6.1, the numbers and percentages of the 789 city's under 16 year olds that are on the Compass and that live in the most deprived and least deprived quintiles are compared. Each quintile has been split into its five percentile subdivisions. (The first subdivision corresponds to SOAs of Brighton and Hove that rank in the 5% most deprived in England for IDACI, whilst the 19th subdivision corresponds to SOAs ranking in the 5-10% least deprived in England.) However, there is no 20th percentile because no SOAs in Brighton and Hove rank in the 5% least deprived in the country for IDACI.

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Table 6.1: Under 16 year olds on the Compass living in SOAs ranking in the most and least deprived national quintiles for IDACI

IDACI ranking of SOAs within England by five percentile steps	Number of under 16 year olds in Brighton and Hove	Percentage of the city's under 16 year olds	Number of under 16 year olds on the Compass	Percentage of under 16 year olds on the Compass	Percentage of the city's under 16 year olds on the Compass
1st	2842	6.98	136	17.24	4.79
2nd	2214	5.43	98	12.42	4.43
3rd	2401	5.89	68	8.62	2.83
4th	2663	6.54	52	6.59	1.95
17th	581	1.43	6	0.76	1.03
18th	524	1.29	7	0.89	1.34
19th	776	1.90	7	0.89	0.90

Data from Table 6.1, on the proportions of under 16 year olds living in SOAs ranking in the most and least deprived quintiles for IDACI, is presented in Figure 6.3. (The quintiles are broken down into their five percentile steps, 1 - 4, and 17 – 19).

All 136 under 16 year olds on the Compass who live in SOAs ranking in the most deprived five percent live in SOAs within or overlapping the housing estates in the east of Brighton. Almost all of the 234 under 16 year olds on the Compass living in SOAs ranking in the most deprived decile live in the east of Brighton (only 14 of them live in the sole SOA mapping in the west).

Greater proportions of the city's under 16 year olds (light blue bars) live in SOAs in the most deprived quintile, than in the least deprived. Overall about 25% of the city's under 16 year olds live in SOAs in the most deprived quintile. In contrast, only about 4% of them live in SOAs ranking in the least deprived quintile (five percentile subdivisions 17, 18 and 19). But, by comparison, the proportions of the under 16 year olds that are on the Compass (dark blue bars) are much higher in the most deprived areas and much lower in the least deprived areas. Nearly 45% of all the under 16 year olds on the Compass live in SOAs in the most deprived quintile, whereas only 2.5% of them live in SOAs in the most deprived quintile.
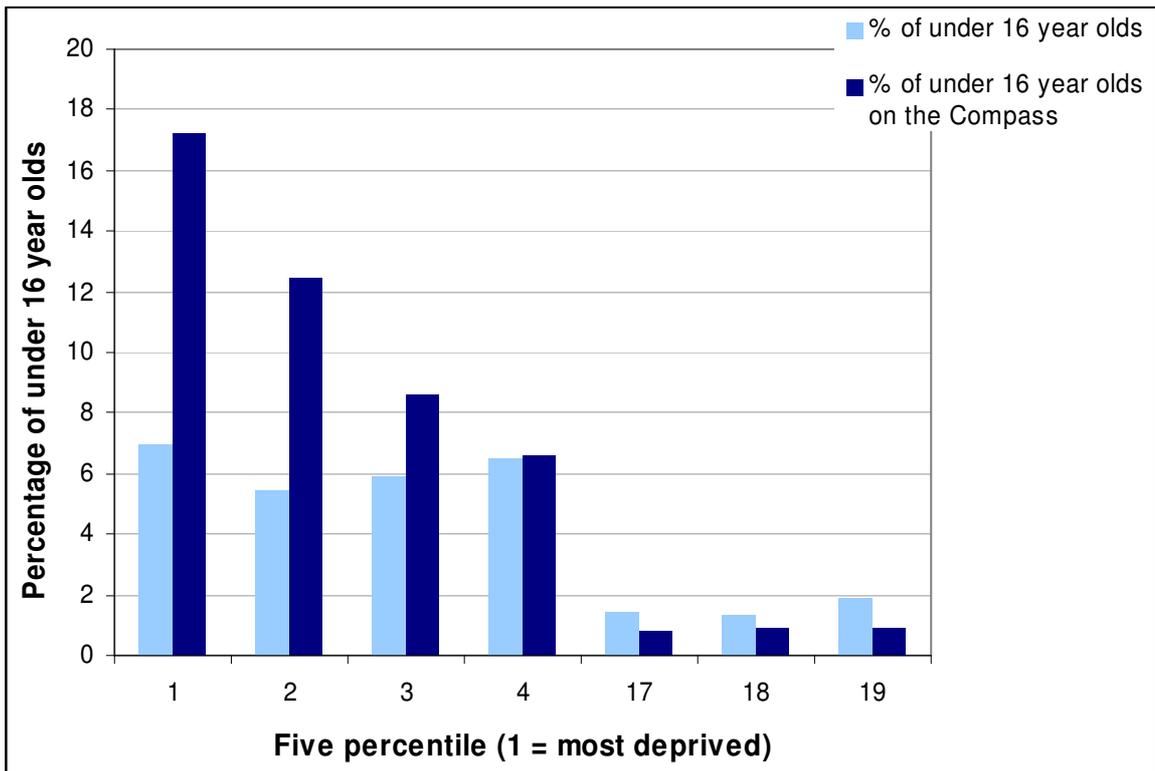
Figure 6.3: Percentages of under 16 year olds on the Compass living in SOAs ranking in the most and least deprived national quintiles for IDACI

In Table 6.1 the percentages of the city's under 16 year olds that are on the Compass have been calculated. They range from 1% of children in the SOAs in the least deprived decile to 5% of children in the SOAs in the most deprived five percentile in England. Remarkably therefore, the proportion of the city's under 16 year olds that are on the Compass is about five times higher in the SOAs that rank in the most deprived decile in England than in those ranking in the least deprived decile.

In the following section Compass registration data was analysed to explore the extent to which under 16 year olds on the Compass who lived in areas with different levels of income deprivation affecting children might also experience different types of potential disadvantage.

6.2 Children on the Compass living in more deprived areas are more likely to experience disadvantage

As the Compass asks parents/carers several questions about their children's family and life circumstances, the responses to salient questions on the child's Compass form were scored alongside the IDACI ranking of the SOA in which they lived. The questions chosen were:

- Do you or another main carer have a disability or long-term health problem?
- Do any other adults have a major share in the care of your child?
- Do you think your child's housing is adequate for their needs?
- How easy was it to complete this form? **Easy / OK / Hard**

As there were many more under 16 year olds on the Compass in SOAs with high IDACI scores, SOAs were split or aggregated (according to their national IDACI ranking) to include broadly similar numbers of children in each group as follows:

- 1a - the most deprived five percentile, (136 children)
- 1b - the second most deprived five percentile, (98 children)
- 2 - the second decile, (120 children)
- 3 - the third decile, (109 children)
- 4 - the fourth decile, (78 children)
- 5 and 6 - the third quintile, (144 children)
- 7 to 10 - the last two quintiles (104 children)

The results are presented in Table 6.2 and Figures 6.2 – 6.5.

Table 6.2: Differences in the family circumstances of children on the Compass living in SOAs ranking in different IDACI deciles

Decile	Housing is not adequate	Child has a sole main carer	A parent/carer is ill or disabled	The Compass form was easy to complete
1a	36.6%	40.3%	50.4%	51.7%
1b	33.3%	41.9%	38.9%	45.8%
2	24.8%	42.9%	43.4%	56.1%
3	26.4%	25.0%	37.6%	55.1%
4	30.8%	15.3%	32.4%	58.1%
5+6	13.4%	18.7%	28.9%	64.3%
7+8+9+10	16.7%	20.2%	29.4%	66.7%
average	25.5%	29.4%	37.5%	57.1%

Whereas the parents/carers of less than 20% of children living in SOAs ranking in the three least deprived quintiles consider their housing is inadequate for their child's needs, higher proportions of those living in SOAs ranked as more deprived report living in unsuitable housing. Inadequate housing is reported by parents/carers of more than one third of the children living in the SOAs ranking in the most deprived five percent in England.
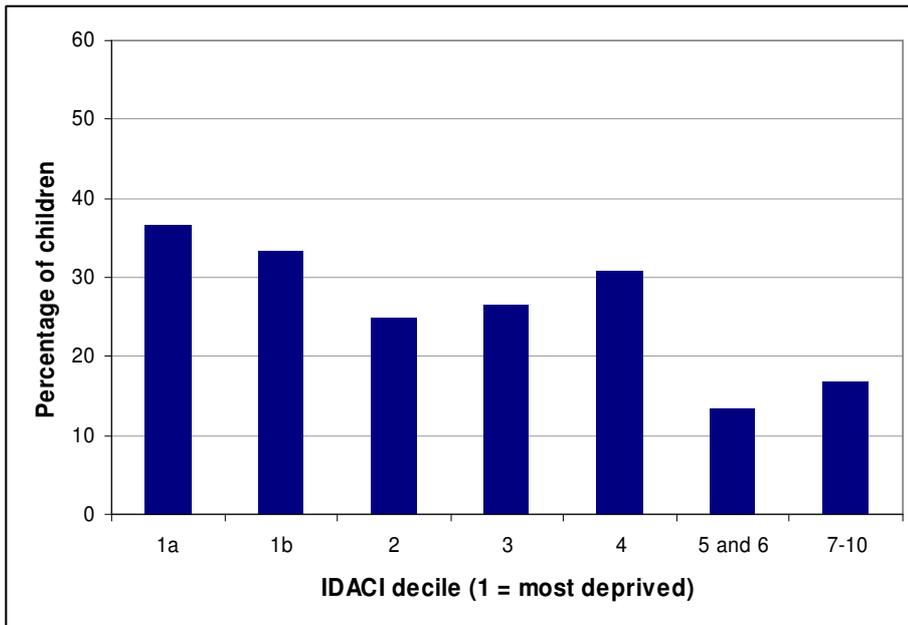
Figure 6.4: Percentages of children on the Compass living in housing their parents/carers consider inadequate for the child's needs
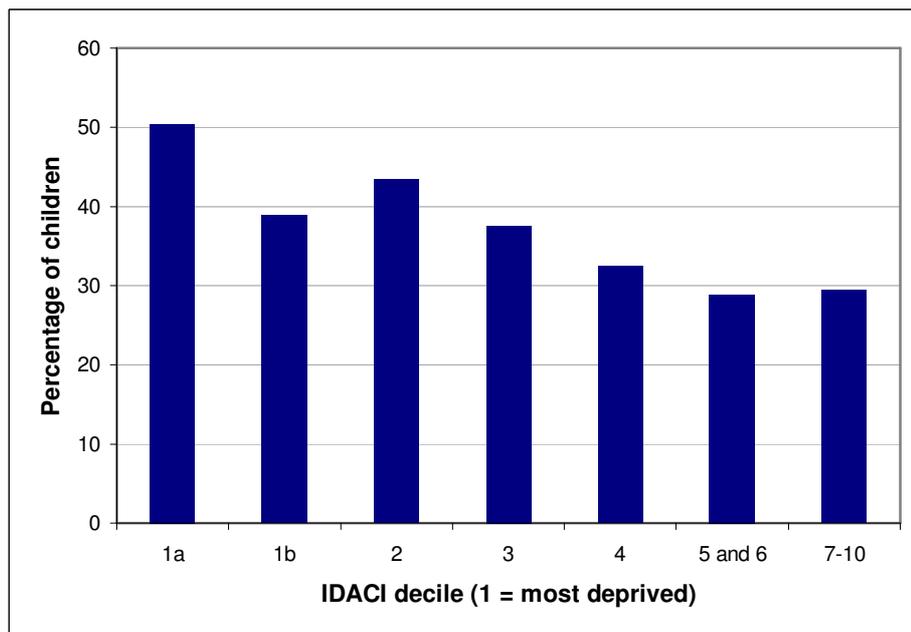
Figure 6.5: Percentages of children on the Compass with a parent/carer who is ill or disabled

Overall a high proportion of children on the Compass have a parent/carer who is ill or disabled. However whilst this applies to about 30% of the children living in SOAs ranking in the three least deprived quintiles in England for IDACI, increasing proportions of children living in the four most deprived deciles have a parent/carer who is ill or disabled. This is the case for over half of the children on the Compass living in SOAs ranking in the most deprived 5% of SOAs in England for IDACI.
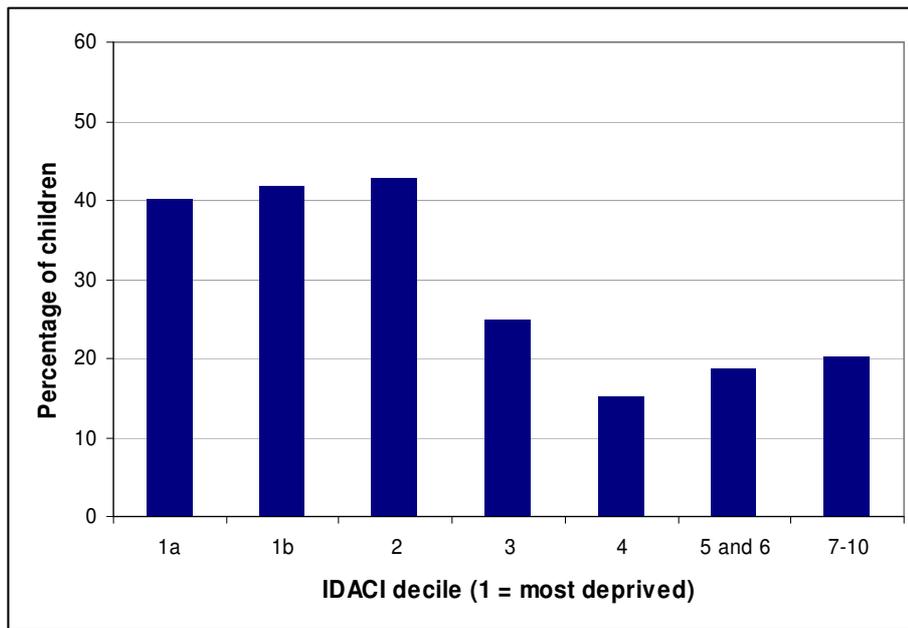
Figure 6.6: Percentages of children on the Compass with a sole parent/carer
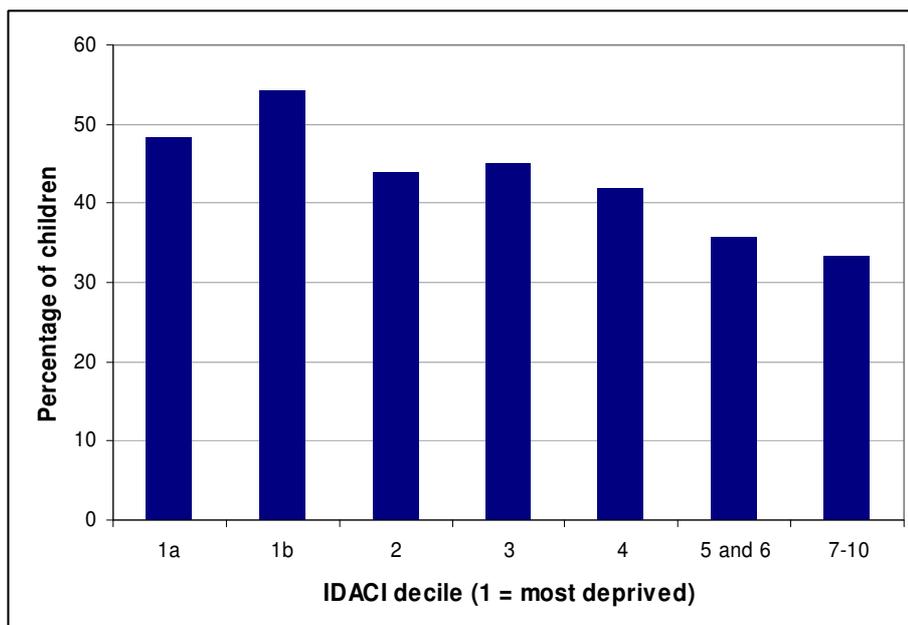
Figure 6.7: Percentages of children on the Compass whose parents/carers did not find filling in the Compass form easy

Whereas fewer than about 20% of children living in SOAs ranking in the seven least deprived deciles have a sole parent/carer, 40% or more of those living in SOAs ranking in the most deprived quintile have a sole parent/carer.

Broadly, the proportions of children whose parents/carers did not find it easy to fill in the Compass form easy were higher amongst those living in SOAs with higher deprivation rankings. Parents can find filling in the form difficult for a number of reasons. They may find it challenging if they have low literacy, if they lack information about their child's condition, or if they find it emotionally difficult to think about their child's additional needs. Amaze has found that parents who do not often communicate in writing, and parents who have only limited information about their child's additional needs, are most likely to say that they did not find the form easy to complete.

In summary, the proportions of children experiencing each of these potentially disadvantageous circumstances tend to increase with increasing deprivation ranking. The exact pattern varies, but the proportions of children affected tend to be highest in SOAs ranking in the most deprived decile, and lowest in those ranking in the least three deprived quintiles. The differences were greatest for the percentages of children living in inadequate housing and having a sole carer – (almost) twice as many of the children on the Compass living in the most deprived decile were affected as in the three least deprived quintiles.

In Table 6.3 the responses from parents of under 16 year olds to more of the questions asked at Compass registration are summarised according to whether children live in SOAs in the most deprived decile or elsewhere in the city. (Of the 789 children on the Compass, approximately 30% - 234 children - live in the SOAs that rank in the 10% most deprived in England for the IDACI.)

The data show that, on average, children on the Compass living in the 10% most deprived SOAs are more likely to experience each of several disadvantages than those living in the less deprived SOAs. For example, they are more likely to have a disabled or ill carer, to have only one main carer, to live in housing that their

parent or carer considers is unsuitable for their needs, and to have been bullied or to have been excluded from school.

Table 6.3: Circumstances of children on the Compass living in SOAs ranking in the most deprived decile compared to those living elsewhere in the city

Compass variable	Under 16 year olds on the Compass living in SOAs in the 10% most deprived in England	Under 16 year olds on the Compass living in SOAs in the 90% least deprived in England
Percentage of children with only one main carer	42.6	31.4
Percentage of children with a main carer who is disabled or has a long term health problem	38.6	23.3
Average number of siblings	2.4	1.7
Average number of siblings with special needs or disabilities	0.8	0.4
Percentage of children living in housing their parents consider inadequate for their children's needs	32.5	19.7
Percentage of children whose main carer found filling in the Compass form easy	41.9	57.2
Percentage of children temporarily excluded from school during the last year	22.7	8.6
Percentage of children permanently excluded from school during the last year	4.7	1.6
Percentage of children informally excluded from school during the last year	31.8	14.2
Percentage of children bullied at school	54.2	42.0
Percentage of children bullied out of school	40.1	23.3
Percentage of children involved in bullying others	32.1	14.5

6.3   The percentages of children on the Compass reported to have ADHD/ADD or an autistic spectrum condition (ASC)

About a quarter of children on the Compass are reported by their parents or carers to have been diagnosed with an autistic spectrum condition (ASC). About 15% are reported by their parents or carers to have been diagnosed with ADHD or ADD. In Figure 6.8 the percentages of the children on the Compass reported to have an ASC, or ADHD/ADD, are compared by deprivation decile. Deciles 7, 8, 9 and 10, making up the two least deprived quintiles, are aggregated because the numbers of children on the Compass in each of these deciles are small.

This figure shows that, of all the under 16 year olds registered on the Compass, the proportions reported to have an ASC (dark blue bars) are lowest in the two

most deprived deciles and higher in the less deprived deciles. In contrast the proportions with ADHD/ADD (light blue bars) are highest in the most deprived decile, about average (for the Compass) in deciles 2-4, and lowest in deciles 5-10. These findings are included here because they highlight another difference between children on the Compass living in more and less deprived areas.
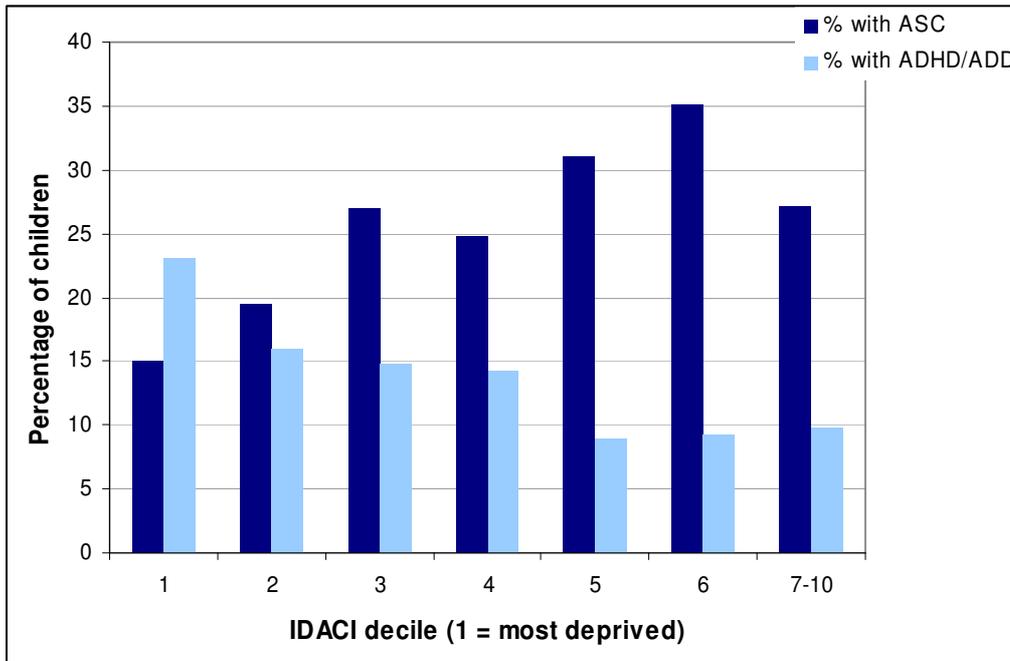
Figure 6.8: Percentages of children diagnosed with ASC or ADHD/ADD

Parents of 49% of children living in SOAs ranking in the most deprived decile (which has the highest proportion of children with ADHD/ADD and the lowest proportion with ASC) found the Compass form easy to complete (see Table 6.3). In fact, for the children in this decile reported to have ADD/ADHD, 46% of parents (18 parents) found the Compass form easy to fill in. In contrast, for the children reported to have an ASC, 72% of the parents (23 parents) found the Compass form easy to fill in. These findings suggest that some of the latter group of families are somehow atypical of families living in these SOAs.

6.4   Children on the Compass and multiple deprivation

Like most national and regional (quantitative) studies, the above analysis does not explicitly explore the circumstances of individual children or their families. It implies, but does not demonstrate, that children on the Compass living in the more deprived areas, are more likely to experience multiple disadvantages. Interestingly, the Index of Multiple Deprivation (IMD), described in the ID 2007 and previous ID exercises, does not actually measure the numbers of people experiencing multiple deprivation. It is constructed by weighting and combining the seven separate domain indices of the ID 2007, so SOAs could theoretically achieve high IMD scores if different subsets of their population experienced different types of deprivation. However, unlike the ID exercises, the Compass collects multivariate data on each person registered. So by reviewing individual Compass records, it is possible to determine whether (and what proportion of) families with children on the Compass experience multiple deprivation.

Four Compass variables were chosen as indicators of deprivation. These were:
- The child has only one main carer
- A main carer is disabled or has a long term health problem
- The carer considers that the child's housing is inadequate for their needs
- The family has more than one child on the Compass

In Figure 6.9 the number of disadvantages each family experienced was scored and compared according to whether the family lived in a SOA ranking in the most deprived decile (for income deprivation affecting children) or elsewhere in the city.

The chart shows that higher proportions of families with children on the Compass living in the 10% most deprived SOAs (blue bars) experience one or more of these four disadvantages than families with children on the Compass living elsewhere in the city (red bars). Over a third of families living in SOAs in the most deprived decile experience two or more of these four disadvantages compared to less than a quarter of those living elsewhere in the city.

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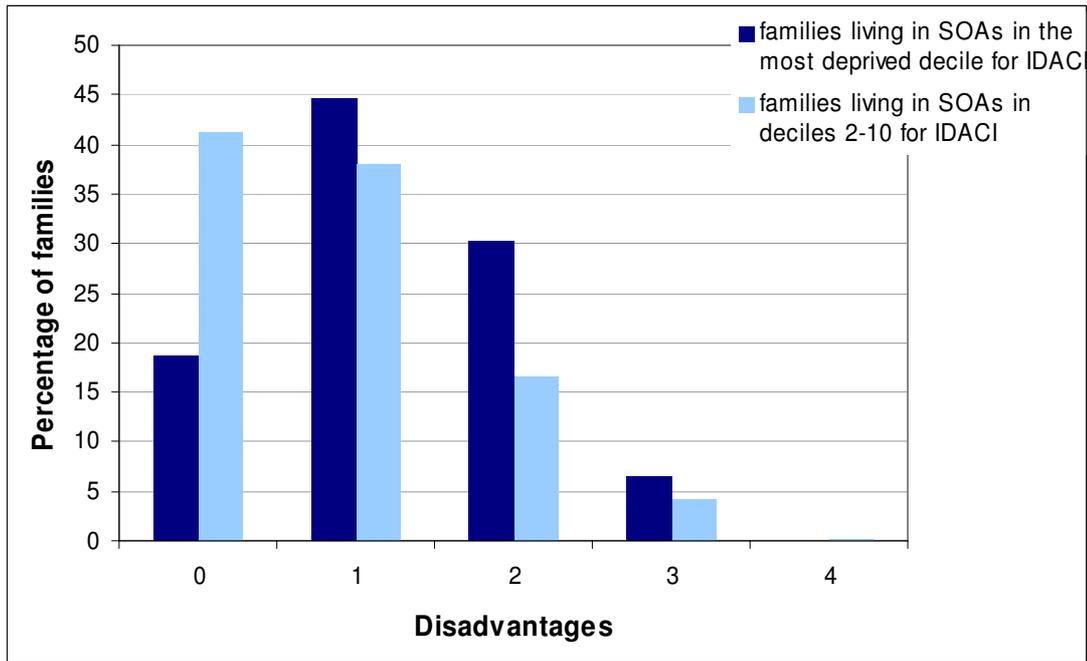
Figure 6.9: The percentages of families with children on the Compass experiencing multiple deprivation

6.5   Conclusions

In this chapter it was shown that in SOAs ranking in the most deprived decile for IDACI, much higher proportions of Brighton and Hove's children are on the Compass than in SOAs ranking in the least deprived decile. The analysis suggested that the prevalence of disability might be about five times higher amongst children in SOAs ranking in the most deprived decile than in the least. The analysis of information provided at Compass registration showed that children on the Compass living in the more deprived areas of the city were more likely to experience each of a variety of disadvantages than those living in the less deprived areas. Notably, those living in SOAs in the most deprived decile were almost twice as likely to have a sole parent/carer, and almost twice as likely to live in inadequate housing, than those in the three least deprived quintiles.

One intriguing finding here is that the proportion of children on the Compass reported to have an ASC is lowest in the SOAs in the more deprived deciles, whereas the proportion reported to have ADHD/ADD is highest. It is possible

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that these findings reflect the true prevalence of these two conditions. However, for both conditions there are no well-defined biological markers and diagnosis depends on subjective psychological assessments (Baird *et al.*, 2003). Significant proportions of children with an ASC display symptoms associated with ADHD, and *vice versa* (Gadow *et al.*, 2006), but the current edition of the Diagnostic and Statistical Manual (DSM-IV) holds that a diagnosis of ASC precludes a comorbid diagnosis of ADHD, making an exclusive diagnosis even more subjective.

In a study designed to assess the validity of ASC diagnoses made by local clinicians and to detect possible missed cases, Baird *et al.* (2006) used screening by social communication questionnaire followed by diagnostic assessment of children with statements of special educational need and/or locally identified as having social or communication difficulties. They found 31 children with ASCs who had not been previously diagnosed amongst the 255 children they fully assessed. The children who received a consensus diagnosis of ASC were more likely to have been previously diagnosed if their symptoms were more severe and less likely to have been previously diagnosed if they lived in more deprived areas. Multivariate logistic regression revealed that the odds of previous identification were increased 5 times (95% CI 1.99–12.7) for those whose parents had completed secondary school education.

Indirect support for a link between economic deprivation and under-diagnosis is provided by Palmer *et al*. (2005), who examined whether the resources allocated to different school districts in the U.S., as measured by district revenue, were associated with an different rates of identification of children with ASCs. They found higher prevalences of ASCs amongst children in districts allocated greater resources. They also noted that districts with higher proportions of economically disadvantaged children had lower rates of identification on average.

The findings of Goin-Kochel *et al*. (2006), who surveyed parents' satisfaction with the process of obtaining an ASC diagnosis for their child, also points to inequity in the process. They focused on the age of the child at diagnosis and the number of professionals parents saw during the diagnostic process. They found

that poorer parental education and income were associated with later diagnosis and greater dissatisfaction with the diagnostic process. They argued (2006: 447):

> "These families may have fewer resources from which to draw support and information and may, in turn, put forth less of a 'push' toward clarifying their children's issues and needs".

And as a result of their findings they recommended (2006: 447):

> "Healthcare and education providers who work with families experiencing disabilities should make every effort to ensure equitable diagnostic pathways for parents and children in lower socioeconomic brackets".

Holt (2004a) examined the multifaceted ways notions of ability and disability were played out in two case-study schools within the same Local Education Authority, both with high proportions of students diagnosed as having 'Special Educational Needs' (SENs), but one being 'physically inclusive', with students drawn from mixed socio-economic and ethnic backgrounds, and the other with an almost exclusively white, and broadly "working class" intake. The SENCO of the latter school commented that many children with SEN were not even on the register because (Holt, 2004a: unpaginated) "they're just normal here to be like that", but would have been if they attended schools in more affluent areas, and she noted "we would only statement the absolute absolutes". It is clear that the way disability is performed in this school does not operate in isolation from socio-economic status.

In the case of Aspergers Syndrome, a high-functioning ASC category, Molloy and Vasil (2002) have argued that this diagnosis emerged at precisely the time that a network of new relationships was developing between parents and schools, as clients, who negotiated and bought the services of a range of autonomous professionals, such as a support teachers, speech therapists, occupational therapists and educational psychologists. Thus the social construction of Aspergers Syndrome conflates a range of different needs: the needs of schools to

maintain order, of some parents to make sense of their child's behaviour, and of therapists to have a common methodology to support their practice.

Thus, the more likely explanation is that ASCs are relatively under-diagnosed in children living in more deprived areas, whereas ADHD is relatively over-diagnosed. Interestingly, we found that amongst children on the Compass living in the most deprived decile, the parents of those who had a diagnosis of ASC were much more likely to find filling in the Compass form easy compared to the parents of the other children. This fits with the findings of Baird *et al.* (2006), who noted that parents' level of education was a pivotal factor in obtaining a consensus diagnosis.

Results presented in Section 6.4 demonstrate that some families with children on the Compass experience multiple deprivation. This is an important demonstration since it is often assumed, based on high IMD scores, that residents experience multiple deprivation, but the alternative explanation, of ecological fallacy, is rarely ruled out. A higher proportion of families living in SOAs ranking in the most deprived decile in England for IDACI experience multiple deprivation than families living elsewhere. As all but one of the SOAs in this decile map in the east of the city, the findings are indicative of the difference between the eastern tract of the city and elsewhere. This, and the above analyses, could be fine-tuned to focus more specifically on whether families in the Moulsecoomb, Whitehawk, Bates and Saunders Park Estates, experience particular kinds of problems.

Here only four potentially disadvantageous circumstances were scored. If questions had been included on the Compass form on parents' income and employment status, and the responses analysed, it is very likely that the difference in the extent of multiple deprivation measured between children living in SOAs in the most deprived decile and elsewhere in the city would have been greater. Although responses to such questions could, arguably, be very valuable in informing service providers about the extent of material deprivation local families with disabled children encounter, it is likely that some parents would be unwilling to answer such questions and as a result fewer families would register their children on the Compass or be willing to place their trust in Amaze.

As part of the comparison of life circumstances of children on the Compass living in SOAs ranking in the most deprived decile with elsewhere the city, the responses to questions on the Compass registration form on bullying and exclusion from school were analysed (Table 6.3). This revealed that a high proportion of children on the Compass are excluded from school and, for those children living in SOAs in the most deprived decile, the proportions are two to three times higher than for those living elsewhere in the city. The proportions of children that are bullied, or involved in bullying others, are also considerably higher for children living in SOAs in the most deprived decile than elsewhere.

Attempts to measure the extent to which adults experience social exclusion often use proxy indicators of material disadvantage (such as the four used to gauge multiple deprivation in this chapter). However, in the case of most children, school makes up a major portion of their lives. In recent years bullying and social exclusion have been highlighted by children and young people as crucial issues in their lives. Children's geographers have begun to observe and engage with the social actors to explore the processes underlying bullying, and exclusion from social groups and activities in school settings, including how children with special educational needs are affected (Newman *et al*., 2006; Wooley *et al*., 2006). However the geographical dimensions have not been much explored. In the next chapter I examine whether the geographies of social exclusion of children on the Compass are uneven, using school exclusion and bullying as specific examples.

Chapter 7

Disability, School Exclusion and
Place of Residence

Introduction

Data presented in the previous chapter revealed that children on the Compass living in the SOAs ranking in the most deprived decile for IDACI were more likely, than children living in less deprived areas within in the city, to experience each of several kinds of disadvantage and were more likely to experience multiple deprivation. In this chapter, one important facet of social exclusion for children and young people, exclusion from school, is considered.

Tackling social exclusion is fundamental to the current government's aims, yet there is no agreed definition of the phenomenon of social exclusion. Indeed, the description proffered by the government's Social Exclusion Unit, when it was set up in 1997, focused on the causes rather than being clear about what social exclusion actually was (cited in Levitas *et al*., 2007: 13):

> 'Social exclusion is a shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health, poverty and family breakdown'

All attempts to define social exclusion recognise it is related to poverty, as a lack of material resources can result in a reduced ability to participate in social networks, and *vice versa*. Levitas (1999) summarises the three main discourses of social exclusion:

- A redistributive discourse sees social exclusion as the result of poverty and sees benefits as a means of reducing it (by reducing poverty).

- An integrative discourse sees paid work as the primary, perhaps only legitimate, means of integrating working-age people into society.

- A moral underclass discourse emphasises moral and cultural self-exclusion from society as the cause of poverty, and focuses on certain groups, such as unemployed people, potentially criminal young men (including truants), and lone parents, especially young, never married, mothers.

Burchardt *et al.* (2002) have argued that, in practice, the main focus of government policy to combat social exclusion has been paid employment, but that other ways of envisioning social exclusion are needed for children and other groups who are not able to access employment. Moreover, when considering children it is also important to consider factors that impact on whether they are likely to become socially excluded as adults.

Morris (2001) asked young disabled people what social exclusion meant to them. They viewed it in terms of not having friends, being listened to, or being able to do the everyday things that non-disabled young people did. There was a strong element of feeling they were a burden, had no contribution to make, feeling unsafe, and being harassed and bullied.

Charities representing families with disabled children have long argued that exclusion from school is a major issue for disabled children. However, until 2000/01, government only published statistics on the numbers of school exclusions of pupils with or without statements of Special Educational Needs (SEN). According to the 2000/01 statistics, pupils with statements of SEN accounted for only about 10% of permanent exclusions from school. But, as there are many disabled children who do not have statements of SEN, this style of reporting obscured the magnitude of the issue of school exclusions for disabled children. In 2002 a new SEN Code of Practice replaced the five-stage model of the 1994 SEN Code with pupils at School Action, School Action Plus or with a statement of SEN. When the 2001/02 data was published, it revealed that although pupils with statements accounted for only 12% of the permanent exclusions, a further 49% of the permanent exclusions were of pupils on schools'

SEN registers (on School Action or School Action Plus). More recent data on fixed-period (temporary) exclusions, which was only reported for secondary schools, revealed that nearly one in every three young people with special educational needs was temporarily excluded, accounted for 55% of the fixed-term exclusions (ONS, 2008).

In a major survey on the mental health of children and young people in Great Britain, Green *et al.* (2005) collated information on over 70 autistic children, and noted that 27% of them had been excluded from school at some point and most had been excluded on more than one occasion. Reid and Batten (2006) reported that over 40% of autistic children, whose parents were surveyed, were bullied at school and noted that they were often excluded for retaliating to ongoing bullying that the school had not dealt with. The Advisory Centre for Education (ACE) is an independent national charity that works to empower parents/carers and promote good practice in the education system. It gave evidence to the Education and Skills Select Committee Inquiry into Bullying (ACE, 2006). ACE reported that over 11% of the 7,000 calls it had received in 2005, from parents about problems with schools, concerned bullying. Often parents said that their child was bullied but that the school did not tackle the bullying and therefore they kept the child at home (where they missed out on education). The school continued to leave the bullying untackled and then threatened the parent with prosecution. ACE also reported that in over 5% of the calls they received on exclusions, parents said that the reason for their child's exclusion was that they had responded (retaliated) to bullying.

The Office of the Children's Commissioner (2006) found that disabled children and those with visible medical conditions can be twice as likely as their peers to become targets for bullying. Research on the relation between childhood disability and bullying indicates that

- children with learning difficulties are at greater risk of being teased and physically bullied (for example, see Mishna, 2003).

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- children with Attention Deficit Hyperactivity Disorder (ADHD) are more likely than other children to be bullied. They also are somewhat more likely than others to bully their peers (Unnever and Cornell, 2003).

- children with medical conditions that affect their appearance are more likely to be victimised by peers (for example see Yude, *et al.*, 1998), and

- children who have diabetes and are dependent on insulin may be especially vulnerable to peer bullying (Storch *et al.*, 2004), and

- obese children may also be at higher risk of being bullied (Janssen *et al.*, 2004).

Recent studies undertaken by the Dyslexia Institute (Rack, 2005: 10) suggest that around "20% of the prison population have some form of hidden disability which will affect and undermine their performance in both education and work settings". Talbot (2008) found that prisoners who had these kinds of difficulties were three times as likely to have been excluded from school as the comparison group. (They were also almost twice as likely as the comparison group to have been unemployed before being arrested and, and over half had attended a special school.)

Bullying and exclusion from school are recognised by academic authors as important types of social exclusion for children and are particularly contentious issues for disabled children, their families and schools. In this chapter these issues are explored from a micro-geographic perspective. In the first section it is shown that a high proportion of children on the Compass were excluded from school, and those who were excluded were considerably more likely to live in the most deprived areas, and to experience various disadvantages, such as having a sole carer or a sick or disabled carer, than those who were not. Next it was found that children on the Compass living in the more deprived areas were more likely to be bullied at school and out of school and they were considerably more likely to bully others. Next it was shown that the school exclusion rates were remarkably high amongst children on the Compass who lived in core SOAs of the East Brighton housing estates, and exclusion was often associated with bullying behaviour. In the final section some of the factors that may need to be

taken into account in order to reduce disabled children's risk of school exclusion and bullying are discussed.

7.1 Exclusion from school of children and young people on the Compass

As school exclusion is the particular focus of this analysis, only data on children and young people on the Compass who were of school age were considered. Starting with the same dataset as used in the previous chapter, the records for the under five year olds and over 18 year olds were removed, leaving a total of 919 children and young people aged five to 18.

The Compass asks parents whether their child has been excluded from school during the last year. As children join at any time of the year and information about them is updated every two years, the Compass obtains a somewhat blurred snapshot in time of school exclusion, which cannot be directly compared with schools' exclusion data. The Compass also asks about bullying, but, unlike the questions on school exclusion, these questions ask whether the child has ever been bullied at school, or out of school, or, because of their special needs, been involved in bullying others. As is apparent from the introduction to this chapter, when parents/carers report to the Compass that their child has been involved in bullying others, this can sometimes reflect retaliation to bullying (that the school is unaware of or has not tackled).

Initially the Compass dataset was examined to see how it broadly compared with the national data.

Government publishes national level schools' data on exclusions for each school year. The numbers of exclusions rather than numbers of excluded pupils are reported, but some pupils are excluded more than once. In 2007/08, about 90% of permanent exclusions were from secondary schools and only about 10% were from primary schools. The most common ages for both boys and girls to be

excluded were 13 and 14. Pupils with SEN were over 8 times more likely to be permanently excluded and about 6 times more likely to be temporarily excluded than those without.

24 of the 919 school-aged children and young people on the Compass had been permanently excluded and 135 had been temporarily excluded from school. So overall 17% of school-aged children on the Compass had been excluded.

8% of the mainly primary school-aged children (5-10 year olds), had been temporarily or permanently excluded during the last year and 23% of the mainly secondary school-aged children (11-18 year olds), had been temporarily or permanently excluded during the last year.). These findings echo those from the nationally reported schools' data in that most school exclusions involved secondary school-aged children.

The proportions of children and young people on the Compass who were excluded peaked at ages 13 and 14, the same as the peak ages reported in the schools' data.

In Table 7.1 some of the information parents reported to the Compass on the circumstances of the children and young people who were permanently or temporarily excluded are compared to those who were not.

The data show that children who were permanently excluded were, on average, more likely to experience a range of disadvantages than those who were temporarily excluded; and those who were temporarily excluded were more likely to experience them than those who were not excluded. For example, 62% of children who were permanently excluded have only one main carer, compared to 48% of children who were temporarily excluded, and 38% of those who were not excluded. There were also gradations in the proportions of permanently excluded, temporarily excluded and non-excluded children who were bullied or involved in bullying others.

Table 7.1: Circumstances of children and young people on the Compass who were excluded from school

	Permanently excluded children	Temporarily excluded children	Children who were not excluded
% receiving DLA	75	77	83
% that are male	83	86	69
% with a sole carer	62	48	38
% with a main carer who is disabled or has a long term health problem	37	38	32
% living in housing their parents consider inadequate for their child's needs	43	27	23
% bullied at school	70	69	48
% bullied out of school	74	45	31
% involved in bullying others	67	58	16
% living in SOAs in the 5% most deprived in England	38	33	14
% living in SOAs in the 10% most deprived in England	46	53	25
% living in SOAs in the 20% most deprived in England	71	66	43
% living in SOAs in the 80% least deprived in England	29	33	57
% living in SOAs in the 20% least deprived in England	0	1.5	2.5

The data also show that much higher proportions of the excluded children live in more deprived areas of the city. Nearly half of all the children and young people on the Compass, who were permanently excluded from school (46%) live in SOAs ranking in the 10% most deprived. Over half (53%) of children receiving fixed-term exclusions live in the most deprived decile. Yet this decile accounted for only 25% of the school-aged children on the Compass.

These data suggest that there is a deprivation effect for school exclusion and for bullying. Therefore in the following section this relationship was investigated.

7.2 Deprivation, school exclusion and bullying

The levels of school exclusion and bullying for children on the Compass living in more and less deprived areas were determined. This was done by calculating the percentages of affected children living in SOAs ranking in each quintile of English SOAs for IDACI. The numbers of children in quintiles 1 – 5 were: 429,

206, 169, 94 and 20, respectively. As there were so few children living in SOAs ranking in the least deprived quintile, quintiles 4 and 5 were combined.

In Figure 7.1 the percentages of children who were excluded (panel a), or were bullied or involved in bullying others (panel b), are plotted.

(a)
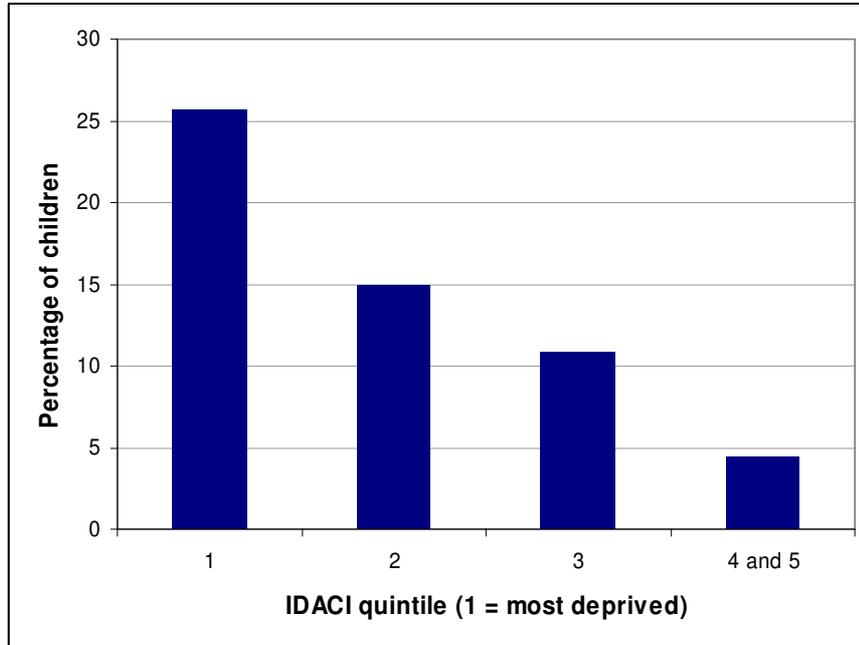
(b)
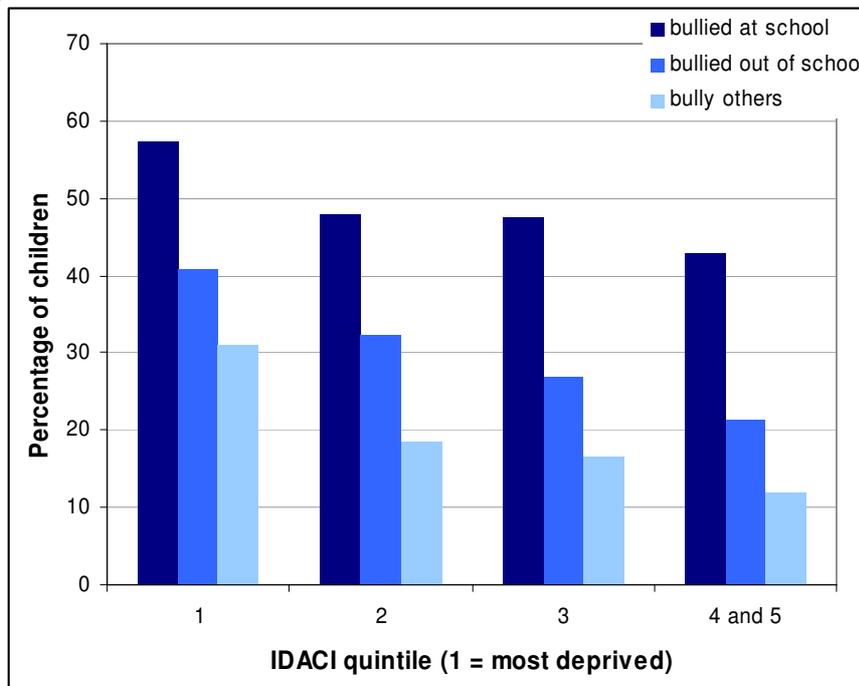
Figure 7.1: Percentages of children on the Compass (a) excluded from school, or (b) bullied or involved in bullying others

Figure 7.1 (a) reveals that higher percentages of the children on the Compass living in more deprived areas were excluded. The differences were remarkable, in that the percentage of children excluded in the most deprived quintile was over five times that in the least deprived. Unless the Compass dataset is highly unrepresentative of the city's population of disabled 5-18 year olds, this in turn suggests that disabled children living in more deprived areas within Brighton and Hove are at much greater risk of school exclusion than disabled children living in less deprived areas.

Figure 7.1 (b) reveals that higher percentages of the children living in the more deprived areas were bullied, and involved in bullying others, than in the less deprived areas. However, whilst the deprivation differential was relatively slight for being bullied at school (blue bars) it was greater for being bullied out of school (red bars) and greatest for involvement in bullying others (yellow bars).

These data suggest a tentative hypothesis that disabled children could be more prone to exclusion if they are involved in bullying others (and perhaps if they are bullied out of school) than if they are not. If this were the case, disabled children living in the more deprived areas would be at higher risk of exclusion because there is a strong deprivation gradient for bullying others (and a noticeable gradient for being bullied out of school).

Remarkably high proportions of children on the Compass who lived in the SOAs making up the core areas of the Moulsecoomb, Saunders Park, Bates Road and Whitehawk estates were excluded from school. Of the 161 children living in the SOAs ranking in the most deprived five percentile nationally for IDACI, 44 had been temporarily excluded and a further 9 had been permanently excluded from school in the last year, so overall 35% of them had been excluded.

Parents of these children reported that
- 71% of the excluded children had been bullied at school, compared to 53% of those who had not been excluded.

- 50% of the excluded children had been bullied out of school, compared to 41% of those who had not been excluded.

- 62% of the excluded children had been involved in bullying others, compared to 25% of those who had not been excluded.

Although based only on a small number of disabled children, these findings reveal that much higher proportions of the excluded children were reported to be involved in bullying others than the children who were not excluded.

Unpicking what the underlying processes might be in the above scenario would obviously be complex. Some disabled children who are reported to be involved in bullying others may actually be retaliating to bullying or may only be peripherally involved whilst major perpetrators escape blame. Schools, neighbourhood environments and both general and specific family circumstances may all play important roles. It is clear from the results presented in the previous chapter that higher proportions of children on the Compass living in the more deprived areas of the city experience a range of disadvantages and are more likely to experience multiple deprivation. An attempt to outline some of the issues is included in the conclusion to this chapter.

7.3   Conclusions

The major finding of this chapter is that a high proportion of children on the children on the Compass are excluded from school, and those living in the more deprived areas are considerably more likely to be excluded than those from less deprived areas. Children living in the more deprived areas are also more likely to be bullied in school and out of school (the deprivation gradient is stronger for the latter), and much more likely be involved in bullying others.

The 2007/08 dataset of Schools' data on exclusions (ONS, 2009), is the first for which any attempt to report on the contingency of school exclusions on area deprivation has been made. Here the IDACI ranking of the SOA that schools are

located in is taken into account. The data, which is on fixed-term exclusions, reveal weaker correlations between levels of exclusion and area deprivation than for the Compass data reported in this chapter. Using the school's address rather than the pupil's address to allocate an area's deprivation status would be expected to obscure the deprivation picture as schools have mixed intakes of pupils. Comparing these two sets of findings raises the possibility that disabled children living in deprived areas may be at particularly high risk of exclusion compared to other disabled children.

Previously, both independent research and the annual schools' data have highlighted that children with SEN and/or disabilities are at greater risk of exclusion than non-disabled children. If schools' data was analysed using the pupil's address as the basis for defining area deprivation, and exclusions were categorised according to whether or not the child had SEN some important insights into whether children with SEN living in more deprived areas experience double jeopardy for school exclusion might be obtained.

The DCSF (2008) published a white paper outlining a strategy for modernising alternative educational provision for young people who had been excluded from school or were at risk of exclusion. In his ministerial foreword, Ed Balls noted:

> "Two-thirds of permanently excluded pupils and 75 per cent of pupils in Pupil Referral Units have special educational needs, and there is more that we can and should be doing to address those needs earlier."

The findings reported in this chapter suggest that many of the affected children and young people lived in deprived neighbourhoods. Unfortunately, the link between (area) deprivation and exclusion, which is likely to be crucial to developing effective strategies to modernise provision, was not made in the DCSF's strategy document.

The issues of bullying and school exclusion are often linked. However, it is only in recent years that bullying has become (more widely) recognised as a major

issue for disabled children. And many anti-bullying websites still tend to neglect the topic of disablist bullying. For example, Coastkid, Brighton and Hove's anti-bullying website for children and young people (http://www.coastkid.org), answers the question 'who gets bullied?' by describing racist, sexual, cultural and homophobic bullying, but disablist bullying is not mentioned. However, the Disability Discrimination Act (2005) now requires schools to pro-actively promote disability equality and eliminate disability-related harassment. Schools and public bodies are required to produce a Disability Equality Scheme to show how they are meeting these new duties. And the Special Educational Needs and Disability Act (2001) makes it unlawful for a school to discriminate against a disabled pupil. In addition, Every Child Matters requires schools to help all children achieve five key outcomes, including staying safe, being healthy and making a positive contribution. In light of this, the question of why so many disabled children are bullied and excluded from school demands careful consideration.

The disability equality duty means that disabled children have the right to be safe from bullying. But some disabled children, particularly those with a learning disability, are unaware of what bullying is; others may know they are being bullied but are too scared, or lack the communication skills, to tell an adult. This problem is compounded because, without specific training, adults may not be able spot when a disabled child is being bullied. They may instead assume that a change in behaviour is part of the child's disability.

When an adult becomes aware that a disabled child is being bullied, they may not do enough because they may not see the incident as bullying, or they may not know how to deal with it, or have the power to do so. Remarkably, the guidance for schools *Bullying: don't suffer in silence: an anti-bullying pack for schools* published by the DfES in 2002, proposed a different strategy for dealing with disablist bullying to dealing with bullying on the grounds of race, gender or sexual orientation. For all but disablist bullying, the strategies included putting in place effective recording systems; multi-agency working with police, youth services and others; and being aware that even young children can understand the consequences of their actions. But strategies for bullying on the grounds of

disability focused more on helping the bullied pupil to deal with the bullying, including teaching assertiveness and other social skills; role-playing in dealing with taunts; and providing special resource rooms at playtimes and lunchtime. Thus it sent out the message that bullying on the basis of race, gender and sexual orientation was wholly unacceptable, but that bullying on the basis of disability was a problem that needed to be dealt with by the bullied child. This guidance has now been withdrawn.

In their 2006 report, the Office of the Children's Commissioner (2006: 5) noted that "New duties on services have introduced important anti-bullying safeguards, although schools retain considerable autonomy".

Reid and Batten (2006), in a survey run by National Autistic Society, found that parents of 44% of autistic children who had been bullied said the school took no action; and for over 16 year olds, nearly two-thirds of parents said no action was taken.

Children's geographers have addressed the complex ways in which inclusions and exclusions are produced, reproduced and challenged in institutional spaces. Holt (2004b) examined the performance of disability within 'inclusive' mainstream primary schools using the ethnographic approach of participant observation and in-depth interviews. Her findings challenge the perception that the simple co-location of children with mind-body differences in the same spaces as 'mainstream' children is sufficient to erode disablism, and she noted disturbing disjuncture between the rhetoric and reality of inclusive schools. Holt found that children who attended therapies or received additional curricular support were most often removed from the subjects they identified as fun, and physically disabled children were often removed from PE and from the playground. Therefore they missed out on the school spaces where most self-expression was allowed and children's cultures were reproduced. Some stayed in formal spaces during breaks to complete specific tasks. All these exclusions can be viewed as ones more generally reserved for punishment.

Another disturbing aspect of Holt's findings (Holt, 2004a) was the potential spatial contingency between social class and the diagnosis of SEN. At a school with an almost exclusively white working class intake, some children's special educational needs were overlooked although they would likely have been on the SEN register if they attended schools with a more socially mixed intake. Schools are allocated extra resources depending on the numbers of children with recognised SEN. Under-resourcing can have a direct bearing on the ability of schools to perform inclusivity, as tackling and preventing bullying of disabled children is resource intensive. If disabled children are bullied but the school cannot offer appropriate support, they are more likely to be moved or excluded. Recently, the tragic circumstances have emerged that led up to the deaths, in Leicestershire in 2007, of Francecca Hardwick, a young person with severe learning disabilities, and her mother Fiona Pilkington, whose bodies were found in a blazing car on a layby. The jury, returning a verdict of suicide on Fiona Pilkington, and unlawful killing for her daughter, decided that the police action contributed to their deaths. Pilkington contacted police on no fewer than 33 occasions in seven years in which youths throwing stones and shouting abuse had kept her family virtual prisoners in their home. The jury also found the local council partly accountable for failing for years to take action against the young gangs, and they criticised the county social services department for not referring Pilkington for professional help after she said she felt suicidal. The Independent Police Complaints Commission has responded by launching an investigation into the way the case was handled, in particular, how seriously the police responded to Fiona Pilkington's calls for help.

Disability hate crime was recognised by law in 2005, but Leicestershire police's policy on hate crime did not even mention disability as a possible spur for abuse until it was rewritten in the wake of the Pilkington case. According to Scope, a similar lack of awareness pervades public opinion; it likens the situation to the general ignorance of race hate crime before Stephen Lawrence's death (Guardian, 2009). Remarkably, as some commentators have argued, it takes a death before such behaviour gains any serious attention.

As well as being at higher risk of school exclusion, disabled children face a range of barriers to participating in leisure activities. These can broadly be classified into financial, attitudinal and accessibility barriers. The finding that disabled children living in the more deprived areas of the city are at very high risk of school exclusion and bullying, and are more likely than those living elsewhere to experience a range of disadvantages that are associated with material deprivation (and social exclusion), prompted the analysis presented in the following chapter into the receipt and need of short break services by children on the Compass.

Chapter 8

Area Deprivation and
Receipt of Short Break Services

Introduction

In July 2006 HM Treasury and the DfES announced a review of children's services that would make recommendations to the Government's 2007 Comprehensive Spending Review. One of the three strands of this review focused on services for disabled children. The prevalence of childhood disability in the UK has increased markedly in the last three decades but funding for provision of social care services has not. The increased prevalence is due in part to medical advances, resulting in better survival rates for severely ill children and very low birth weight babies (Taylor *et al.*, 2000). In the UK for example, whereas 27% of extremely premature babies survived in late 80s, by the mid nineties 42% survived. However, 50% of babies weighing less than 1500g at birth later showed cognitive impairments. There have also been marked increases in the diagnosed prevalence of certain types of conditions, most notably autistic spectrum and mental health conditions.

A cross party panel of MPs received evidence at three public hearings (on early years services, family support and children's services, and transition to adulthood), as well as written submissions from parents, professionals and disabled children and young people. The paucity of services that provide parents with respite from their caring responsibilities, in particular residential short breaks, was the biggest single cause of unhappiness voiced by families at the public hearings.

The report, *Aiming High for Disabled Children*, which resulted from the Treasury Review (HM Treasury, 2007), set out the Government's commitment to

create a step change in the provision of short break services and identified significant additional funding for this purpose. A Pathfinder Programme was established to develop local vision to create the transformation sought by disabled children and their families. The DCSF invited children's services departments, in partnerships with Primary Care Trusts (PCTs), to submit expressions of interest in becoming part of the Pathfinder Programme for short breaks provision for disabled children and young people. Brighton and Hove was among the 21 successful local authorities. Amaze has worked closely with the Children and Young People's Trust (CYPT) to help them plan how the funding should be used. The government's expectation is that the money targets children with complex needs, and is used creatively to expand choice and promote inclusive services.

An analysis of the information parents and carers have given the Compass about their families' receipt and need of leisure services, and of other short break services, such as residential short breaks, and related services, such as Direct Payments, is presented in this chapter. For disabled children and young people short break services provide opportunities to have fun and make friends and therefore represent a crucial element of their social inclusion. Since there was an area effect on school exclusion it was pertinent to ask whether the receipt of short break services was also subject to area effects. However disabled children have a range of support needs, so in the first section a strategy for crudely grouping the children according to the severity of their needs is presented. In the following sections the receipt and need for leisure services and more traditional 'respite' services was analysed. This revealed that, apart from the children with the most severe needs, few children received adequate leisure and short break services. Moreover, those with the most severe needs who lived in the more deprived areas appeared to be more likely to miss out on services. In the next section the uptake of Direct Payments was found to be remarkably skewed towards families living in the less deprived areas of the city.

8.1   Differential Analysis Based on Severity of Special Needs

The Compass admits children who live or go to school in Brighton and Hove or are looked after by the city. In July 2008 there were 1,025 children living in Brighton and Hove and a further 5 of those living outside the city were looked after by Brighton and Hove. Children on the Compass have a range of needs, and only those with the more severe and/or complex needs may require certain short break services (such as residential respite care). Therefore it was important to group the children in a way that could, even crudely, reflect the differences in the severity of their special needs. The approach taken was to categorise them into three groups on the basis of what types of schools they attended. These groups were:

Group 1: This group consists of 116 children. They attend the following schools:

- Hillside
- Chailey Heritage
- Downs View Link College
- Downs View
- St Johns

This group of schools includes schools that offer a curriculum modified for children with profound and multiple learning difficulties, severe learning difficulties and complex needs, including medical needs and physical disabilities.

Group 2: This group consists of 189 children. They attend the following schools:

- Downs Park
- Patcham House
- Cedar Centre
- Hamilton Lodge

This group of schools includes schools that offer a curriculum modified for children with moderate learning difficulties, children with severe hearing impairments and children regarded as emotionally and/or physically fragile.

Group 3: This group consists of 725 children. They attend the following schools:

- local mainstream schools and preschools
- Units attached to mainstream schools
- ACE
- PRESENS
- Out of area special schools
- Not attending pre-school, school, or college (too young, too old, home-educated, excluded)

ACE, the Alternative Centre for Education, caters for children with emotional and behavioural difficulties. A few children attending out of area special schools have complex and severe needs, but, on average, children in Group 3 have less complex special needs and lesser support needs than those in Group 2.

It is important to stress that the analysis presented here is of information parents/carers provide on their child's Compass form. But there are a number of reasons why some parents may fail to tell us that their child is getting a leisure or short break service. For example, they may have forgotten to mention it or they may not recognise the service by name. Similarly, some parents may fail to tell us of services their child needs. For example, parents may give up asking for services that they suspect their children are unlikely to ever receive. This reporting issue is considered in later sections of this chapter.

For each of the three groups of children, the proportions of children living in SOAs ranking in each deprivation quintile within England (for IDACI) were compared. The results are shown in Figure 8.1. Compared to the other two groups, the distribution of children on the Compass attending the schools designed to support children with the severest and most complex special

educational needs is skewed towards those living in the less deprived areas. This is perhaps surprising, as poverty is known to be a major determinant of child ill health. Social class gradients have been noted for a range of conditions, including congenital abnormalities, cerebral palsy, asthma, moderate learning difficulties, and mental health disorders (summarised in Spencer, 2008). However, the distribution of Group 1 children shown in Figure 8.1 may not necessarily be representative of the overall distribution for children attending these schools. For example this kind of bias would arise, if parents of children with the most severe needs who live in the less deprived areas are more likely to find out about Amaze and to register their child on the Compass. As schools hold data on where children live, it would be straightforward (if the data was made available, for example, at SOA level) to determine whether there are demographic biases in special school attendance. Virtually all children attending special schools have statements of SEN. Some (limited) Schools' Census data on pupils with SEN is published at national level. This revealed that 24.5% of those with statements were eligible for free school meals compared to 29.4% of those on School Action Plus (ONS, 2008). This difference is compatible with the possibility that there is a bias in the statementing process, which favours children from less deprived families.
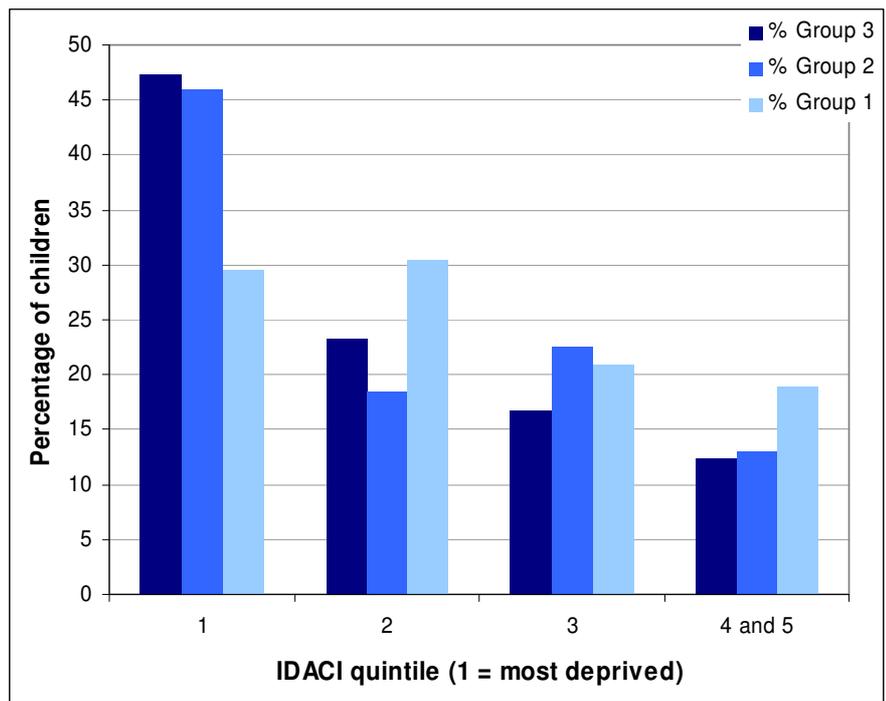

Figure 8.1: Area deprivation and types of school attended by children on the Compass

8.2   Receipt and Need of Leisure Services

The compass registration form contains questions asking parents/carers whether their child attends or needs:

- After School Playschemes (ASP)
- Holiday Playschemes (HPS)
- Sports and Leisure Clubs (SL)

In Table 8.1 and Figure 8.2 the percentages of children in each group, whose parents reported that they got one or more types of leisure service, or that they needed the service but didn't get it, are shown. The groups of children are arranged in the order of least (Group 3) to most severe needs (Group 1).

Table 8.1: The percentages of children reported to attend or need leisure services by group

	attend ASP	need ASP	attend HPS	need HPS	attend SL	need SL	attend ASP or HPS or SL	need ASP or HPS or SL
Group 3	7.6	11.2	6.9	16.3	8.7	18.5	17.7	22.5
Group 2	10.6	13.2	13.8	15.9	19.0	22.2	29.1	24.9
Group 1	32.8	15.5	37.9	19.0	10.6	19.6	54.3	20.7
All Children	11.0	12.0	11.7	28.2	10.6	19.6	23.9	22.7

Data in the last row of Table 8.1 show that, overall, very low proportions of children on the Compass appear to receive each of the three categories of leisure activities. Of the three types of leisure service, the greatest reported unmet need is for holiday playscheme places.

These data suggest that, apart from the children in Group 1 (who attend Hillside, Downs View, Downs View Link College, Chailey Heritage or St John's), very low proportions of children on the Compass attend after school playschemes or holiday playschemes.

Surprisingly few of the children in Group 2 (who go to Downs Park, Patcham House, Cedar Centre or Hamilton Lodge schools) apparently attend after school playschemes or holiday playschemes (fewer than one in eight of them). The proportions of children in this group who are reported to attend after school or

holiday playschemes are more similar to the proportions in Group 3 (with, overall, the least severe needs) than to those in Group 1 (with, overall, the most severe needs).

Whereas parents of over 30% of the children in Group 1 report that their child attends an after school playscheme or holiday playscheme, only about 10% of them report that their child attends a sports club or leisure club.

Figure 8.2 (b) shows the percentages of children whose parents say they need, but do not get, each type of leisure service. The real unmet need is almost certainly higher than shown here because the idea of attending leisure activities is likely to be 'off the radar' for some families (for example, those with very pressing concerns about their child's diagnosis or ongoing care needs, and those in financial difficulties). Nevertheless, some parents express unmet need for each of these three categories of leisure services. For every child in Group 3 (the group with, on average, the least severe needs) whose parents tell us they attend a holiday playscheme, there are another two children whose parents tell us they don't attend but need to.

These data cannot convey anything about the level of satisfaction parents have with the leisure services their children attend. Overall parents of about one in five children who received a leisure service said they needed more of the service or a somewhat different service. The actual proportion is likely to be higher, as parents are often grateful for their children to be receiving any support. A selection of their comments are summarised and discussed at the end of this section.

(a) Reported receipt of leisure services
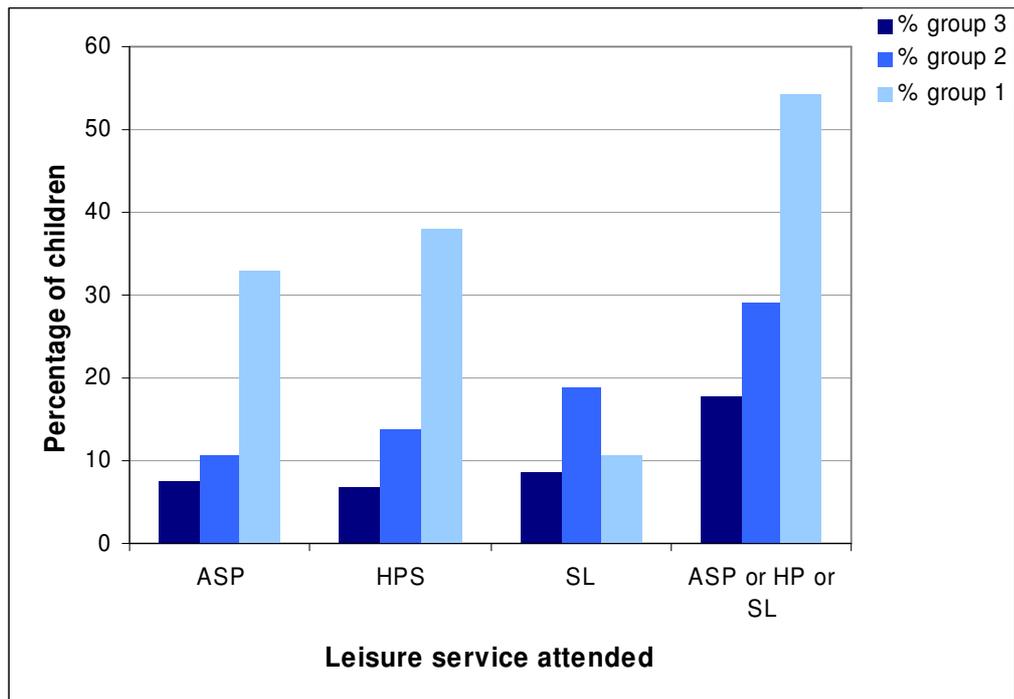
(b) Reported need for leisure services
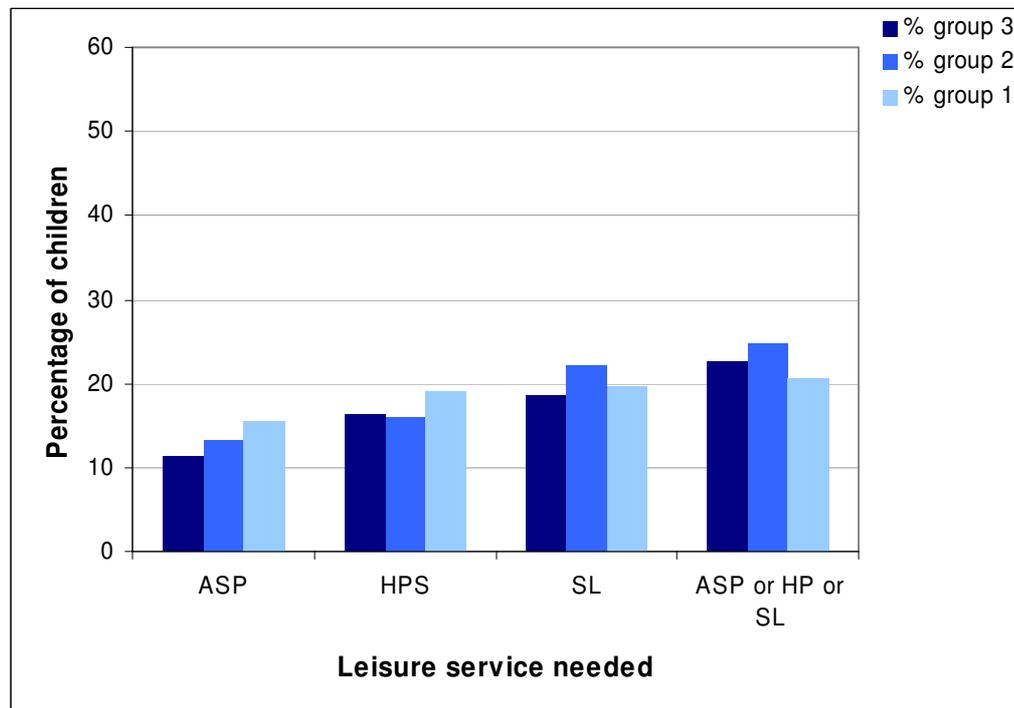
Figure 8.2: The percentages of children reported to be receiving or needing leisure services by group

In Figure 8.3 the age ranges of children in Group 1 and Group 3 who we were told attend each type of leisure service are compared.

(a) Group 1
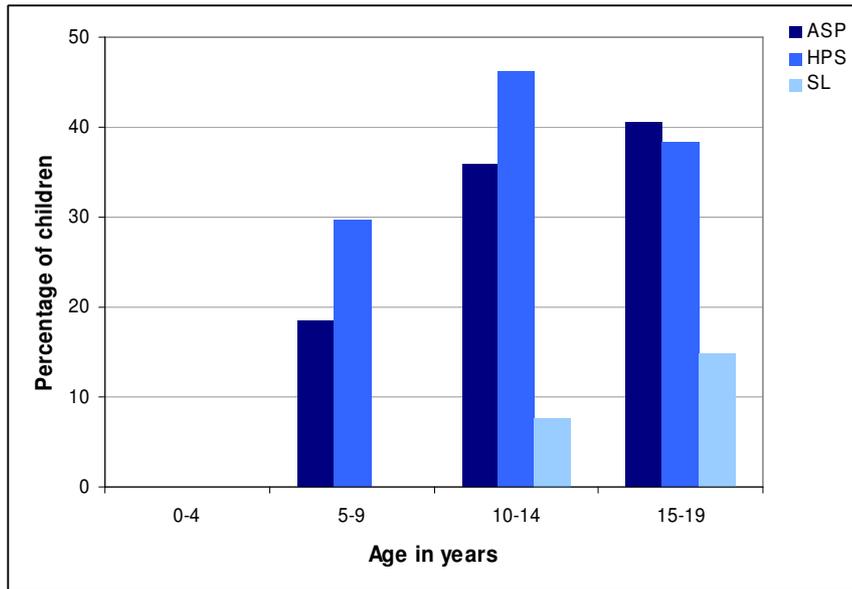
(b) Group 3
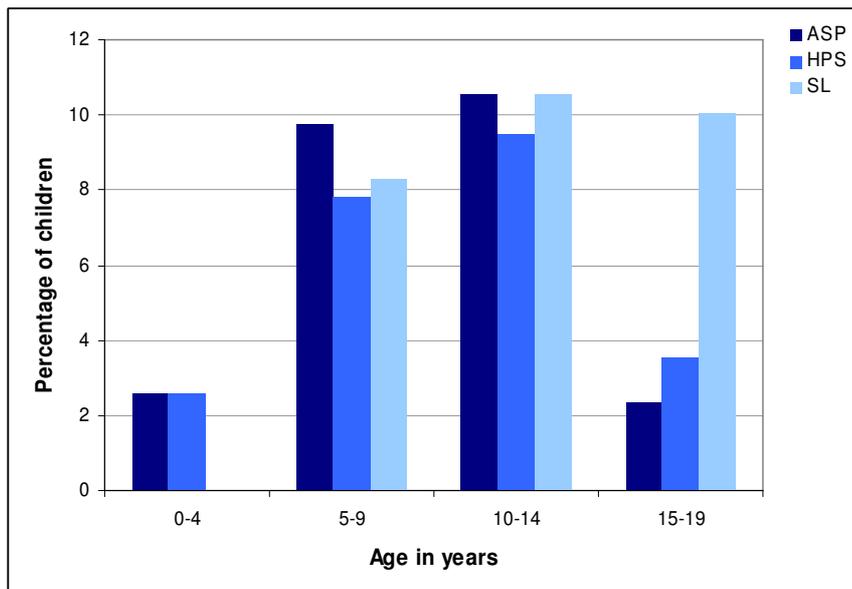
Figure 8.3: Differences in the ages of children with, overall, the most and least severe needs who were reported to attend leisure activities

Figure 8.3 (a) suggests that, amongst the children with the most severe needs, the proportions of over 14s and of 10-14 year olds that attend after school playschemes or holiday playschemes aren't very different. In contrast, Figure 8.3 (b) suggests that amongst the children with, on average, the least severe needs (Group 3), the proportions of over 14s that go to after school playschemes or

holiday playschemes are much lower than both the proportions of 10-14 year olds and of 5-9 year olds.

Apparently, the group of children with, on average, the most severe needs is the only group in which reasonably high proportions of the children attend holiday playschemes.

In Figure 8.4 the percentages of the children, in each IDACI deprivation quintile, who were recorded as attending holiday playschemes, are shown.
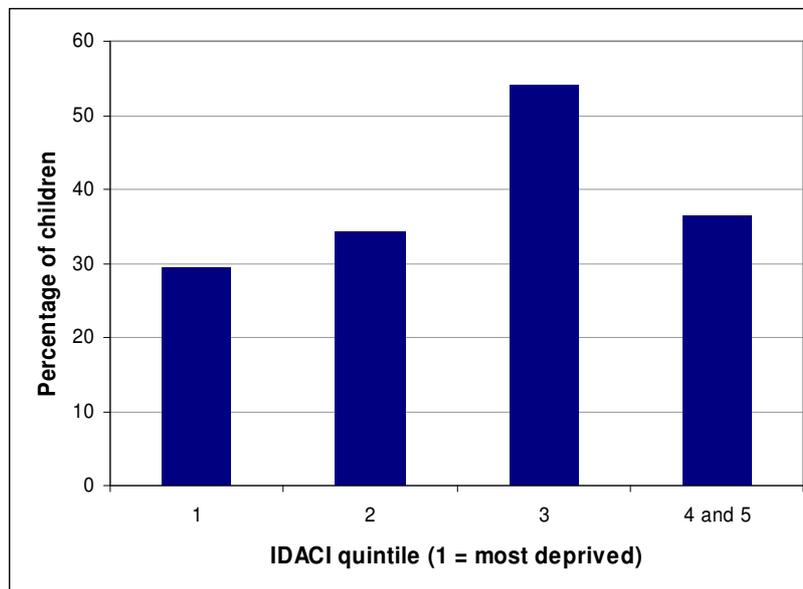
Figure 8.4: Holiday playscheme attendance by deprivation quintile for children in Group 1

The numbers of children involved are low, (10 out of 34, 12 out of 35, 13 out of 24, and 8 out of 22 attending HPS in quintiles 1, 2, 3, and 4+5 respectively). However, the analysis is at least suggestive that, amongst the children with the most severe needs, those who live in areas with the greatest income deprivation are the least likely to attend holiday playschemes.

Some of the comments parents and carers made about the different types of leisure services are summarised in tables 8.2 – 8.4. The school or school group the child attends and the IDACI decile they live in are included alongside the

comments. Male children are referred to as M and female children are referred to as F.

Table 8.2: Carers' comments on after school playschemes

Comments	Child's circumstances
We pay for M to attend Extratime	decile 2
We need affordable after school clubs	decile 1 at Downs Park
He's too old and we have no transport	in 15-19 age range
Moulsecoomb Neighbourhood Trust - we have to send F there for respite	decile 1 older carers
Moulsecoomb Neighbourhood Trust – which we pay for	decile 1
They are inappropriate as M is autistic, and can't cope with noise	at Downs View
Haven't attended these as M would miss his transport	at Downs View
M goes to Extratime. But in general more places and more funding is needed for After School Clubs	decile 1 at Downs View
M goes to his mainstream school's After School Club. I am worried there might not be suitable after school and holiday care once M goes to secondary school	decile 2
After school playschemes are needed for able children with special needs	
M attends Extratime - we pay for him to attend as many schemes as possible so that he is with other young people - because he cannot play out alone and we are older carers	decile 4 at Hillside
My child did go to Extratime but I can no longer afford it	decile 3
I couldn't afford it and M not happy	decile 1
After school playschemes are needed especially for children with ADHD	decile 1 in Group 1

Table 8.3: Carers' comments on holiday playschemes

Comments	Child's circumstances
Attends Extratime at Hillside one day per week; but could always do with more help in school holidays	at Hillside
More places and more funding needed	in Group 1
More information is needed on outings during the summer holidays	in Group 1
More activities are needed for children with PMLD, especially in the school holidays	at Downs View Link College
My child attends Cherish. More schemes are needed	decile 6
The city needs an autism specific holiday club	at Downs View
We desperately need a holiday playscheme – we have no money and no garden and M is isolated (he has Aspergers)	decile 3
Holiday Playschemes are needed for youth/teens in East Brighton	decile 1
Desperate for this but we lack funds as we are on benefits	decile 3
Wants any that are affordable	decile 2
Very limited for teenagers – most holiday clubs end at age 12 – it's difficult if your child is older but emotionally, etc, is still very young	
Would like information on what is available	
What is suitable for my child?	

Table 8.4: Carers' comments on sports and leisure clubs

Comments	Child's circumstances
Buddy/befriending service needed. Teenage clubs and social support needed	decile 2 in Group 2
Youth club needed with peers to learn to socialise	at Downs View
Need information on what is available	decile 4 at Downs View
Weekend playgroups for F's age are not there - they are for the little ones	decile 6 middle of 10-14 age range
F needs swimming/physical activities out of school that are appropriate – as she doesn't walk she needs loads of physical exercise	decile 6 in Group 1
Would love special needs sessions at swimming pool, or hydrotherapy. Also horse riding	at Chailey
Specialist youth provision for children with ADHD locally would be good	decile 1 at Downs View
Attends Seagulls Specials; needs more sports – needs lots of exercise as weight gain due to steroid treatment	decile 2
More clubs and transport needed	decile 2 at Downs View Link College
Financial need prevents holidays/days out (would need transport)	decile 6 at Downs Park
would benefit from regular gym exercise to strengthen muscles after treatment	decile 1
weekend/social club to develop social skills; safe chat room/website for kids with Aspergers	decile 5
want to find any sport or physical activity M can do (he has Aspergers) that take into account his social impairments	decile 3
want leisure activities for and with other kids with ASD	
Needs some sort of activity, but not into football	
More clubs for teenagers are needed	decile 2
Went to drama group 'Impact' in Lewes – but couldn't afford it anymore	decile 1
Did Carousel music course for one year - would like it to continue - it is great	
Needs (integrated) dance and drama clubs	at Downs Park

For each of these three types of leisure service some parents commented that they could not afford the activity and/or the transport to get to or from it. Although most of these parents lived in SOAs in the most deprived quintile, some who lived in less deprived areas also commented on not being able to afford the activities. Some parents did not know what was available and suitable for their child and some felt that the choice of activities or the number of sessions was too restricted.

Some themes emerged around the need for particular types of leisure schemes or activities to cater for particular groups of children:

- for children on the autistic spectrum.
- for children with ADHD.

- for children and teenagers who need more exercise.

- signing support to include deaf children.

- youth clubs for older children and teenagers with learning difficulties.

- buddying schemes for teenagers who want to improve their social skills and go out into the community, but would need support to do so safely.

- more activities that severely disabled children can access, including (inclusive) drama / arts / music schemes, horse riding, swimming at hydrotherapy pool (for children unable to access public pools).

- After School Playschemes and Holiday Playschemes for over 12s.

8.3   Receipt and Need of Short Break Services

In the previous section the receipt and need of leisure services was considered. In this section the focus is on the following services:

- Residential Short Breaks (SB)
- Link Plus (LP)
- Outreach
- Crossroads (CR)
- Direct Payments

Further information about these types of short break services is given in Table 8.5.

Table 8.5: Short break services for disabled children

Service	Aim, Overview, and Access	Further Information
Residential Short Breaks	To offer regular short overnight residential breaks to children and young people with disabilities. This provides an opportunity for both the family and child to have overnight breaks. Children have overnight stays stay at local residential homes. The emphasis is on a personalised service where children are encouraged to express their wishes and views. Staff are trained and supported to meet the individual needs of the children and young people. Residential Short Breaks are accessed via the Social Care service. There is always a heavy demand and most families have to wait a long time for a place.	One local site is equipped for children who have severe learning disabilities and physical disabilities (lifts to upper floor, overhead hoists where required, a computer with adapted technology). Another is for disabled children who have challenging behaviour and may also have severe learning disabilities. A range of activities are offered including use of a sensory room, soft play room, (adapted) garden activities.
Link Plus	A scheme developed by the Social Care service and run by Barnardo's, with the primary aim of supporting families to continue to care for a disabled child in their own homes. Link Plus matches and links a family with a disabled child to a family who can help share in the care of the child by welcoming them into their home. This enables both the family and the child to have regular breaks. Link Plus is accessed via mainstream Social Care services if a child has a moderate disability or via the disabled children's social work team if a child is severely disabled or has a moderate disability with challenging behaviour/mental health needs. Most families have a long wait for a place.	The short break can be during the day or an overnight stay once or twice a month, depending on the needs of the child and their family and what the carer can offer. All carers are encouraged to support the family and to enrich the child's life socially, by accessing activities in the local community and spending positive time with the visiting child.
Outreach	Outreach is a social care service for children aged 2-18 with moderate to severe disabilities. It supports children to access activities and events in their local community. It can also provide essential crisis intervention support to families who may be close to breakdown, or where there may be child protection and safeguarding issues. The service is accessed via a social work assessment.	Outreach is offered on an individual or group basis after school, at weekends and also during school holidays. Workers often have skills gained in other settings such as education, residential homes, afterschool clubs and holiday schemes.
Crossroads	Crossroads is a voluntary organisations whose workers helps support people who care for a disabled, ill or elderly person at home. give carers a break. The aims are to relieve stress in families or individuals responsible for the care of a disabled person by giving carers a break, and to avoid sending the disabled person into hospital/residential care because of the difficulties of caring at home. Parents can self-refer or be referred by a professional (such as a GP or Health Visitor). There is usually a long wait, depending on current levels of funding and staffing.	Crossroads workers take over the caring role for a few hours in the carer's home to give them a break. This can be on an occasional or regular basis, when help is most needed - weekdays, weekends, evenings. The Support Workers come and play with the child and can help with their personal care needs (washing and dressing, wheelchair pushing, feeding).

Direct Payments	With Direct Payments parents and carers, or young people aged over 16, receive money from the Children and Young People's Trust to enable them to buy in support, instead of receiving a pre-arranged service. This scheme aims to put carers in control of the services provided for their child. Direct Payments are favoured by parents whose child has been assessed for a service but has been on the waiting list and getting no help for a long time, or is receiving an inappropriate service because it is all that is offered, rather than getting what they really want. Direct Payments are allocated following a social work assessment where a need has been identified. They are available alongside other support services.	Users of Direct Payments are required to keep accounts and records of how the money is spent and take responsibility for finding the person to look after their child. They will have legal obligations as an employer. The amount of money should cover the cost of that service if run by the Council. If there is no local service, parents may have to negotiate with the local authority what the reasonable cost of providing it is.

The Direct Payments scheme is relatively new, and very few families are so far using it, so data on the receipt of and need for Direct Payments is very limited. Therefore this service is considered separately at the end of this section.

Table 8.6 and Figure 8.5 shows the percentages of children that are reported to receive each of these short break services.

Table 8.6: The percentages of children reported to receive short break services by group

	Residential Short Break (SB)	Link Plus (LP)	Outreach	Crossroads (CR)	Receive one or more of these four services
Group 3	2	3	1	1	6
Group 2	3	7	3	3	13
Group 1	28	21	27	15	58
overall	5	6	5	3	13

Data in the last row of Table 8.5 show that overall only a low proportion of the children on the Compass (less than 6%) appear to get any one of these four short break services. As one would expect, parents of much higher proportions of the children in Group 1 report that their children get one or more short break services. As with after school and holiday playschemes, the proportions of children in Group 2 (attending Downs Park, Patcham House, Cedar Centre and Hamilton Lodge schools) who get short break services appear to be considerably lower than those in Group 1 and much more similar to the proportions of children in Group 3 with (on average) the least severe needs.
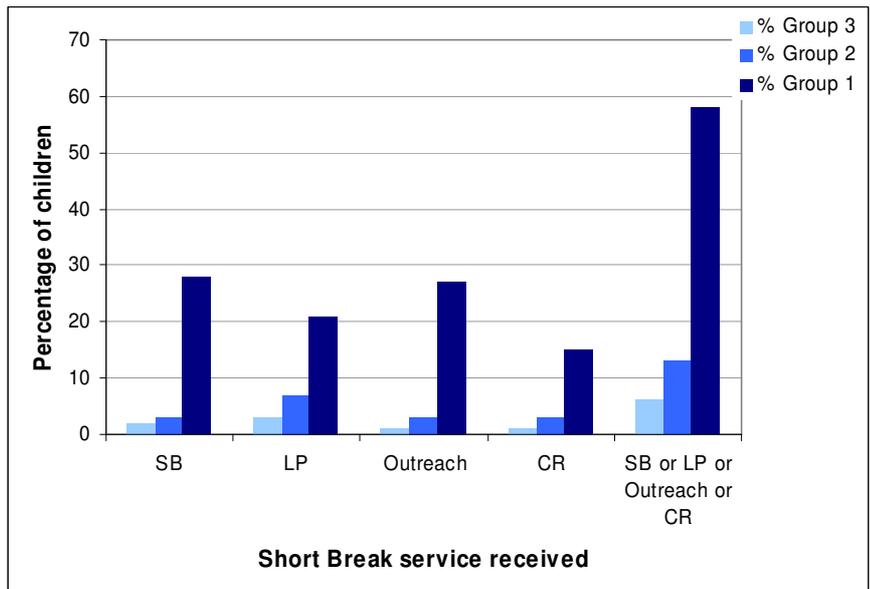
Figure 8.5: The percentages of children reported to receive short break services by group

Overall, parents of 135 children told us their child got one or more of these short break services:

- 1 child was reported to be getting all four of the above services.
- 5 children were reported to be getting three services – 4 of them are in Group 1.
- 39 children were reported to be getting two services – 29 of them are in Group 1.
- A further 90 children were reported to be getting one service. – 34 of them are in Group 1.

Of the four types of short break service considered in this section, the largest unmet need that parents reported to the Compass was for residential short break services. The data in the following table and chart show the percentages of children in each of the three groups, and overall, on the Compass, whose parents said that they got or needed residential short breaks. Except for the group of children with, on average, the most severe needs, the numbers of children whose parents said they needed residential short breaks exceeded the numbers getting them at least three-fold.

Table 8.7: The percentages of children reported to receive or need residential short breaks

	Percentage receiving residential short breaks	Percentage needing residential short breaks
Group 3	1.7	7.2
Group 2	3.2	10.1
Group 1	27.6	9.5
All children	4.9	8.0
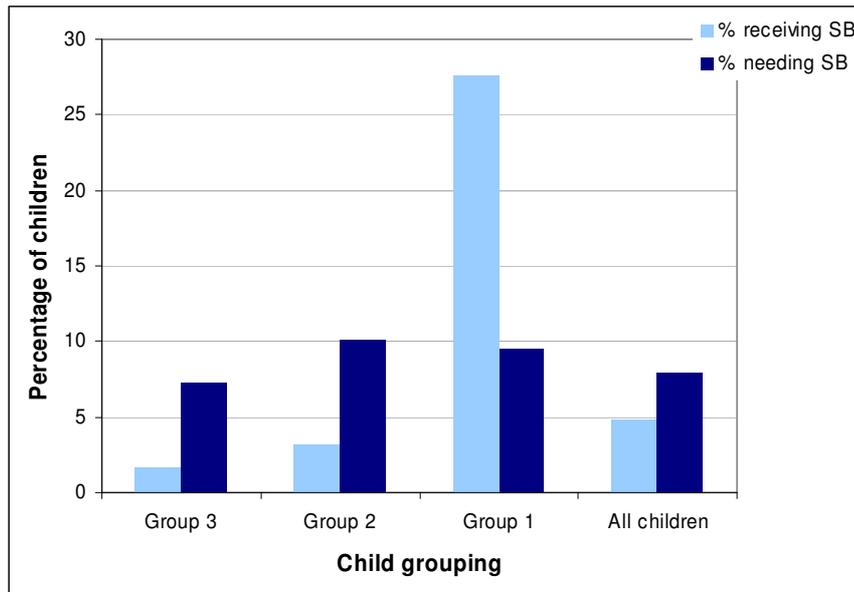
Figure 8.6: The percentages of children reported to receive or need residential short breaks

In Figure 8.7, data on the receipt of the different types of short break services by children attending selected 'Group 1' schools (Hillside School, Downs View Link College and Downs View School) and the 'Group 2' school, Downs Park School, are compared. (Here children at Hillside School and Downs View Link College have been considered in the same group because the numbers of children at each of these schools is low.)

The proportions of children at Downs Park School who we were told get each short break service are much lower than at Downs View or Hillside and Downs View Link College. Although children attending this school have, on average, less severe needs than those at the other schools shown here, their needs are still substantial. But parents of less than one in six of these children report that their child gets any of the short break services shown, compared to 50% or more of the children at Downs View, Hillside and Downs View Link College.

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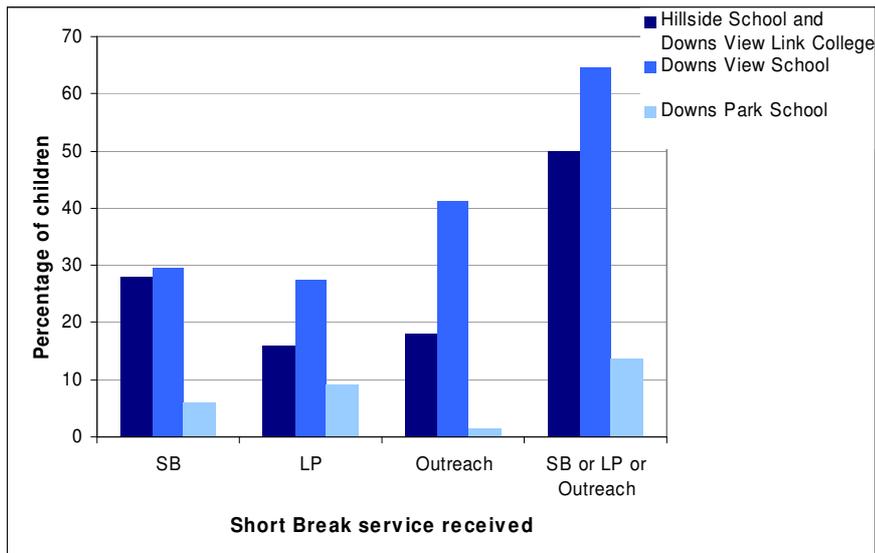
Figure 8.7: Receipt of short break services reported for children attending different special schools

The Compass includes 3 looked after children who go to Downs Park School. Foster parents of all of them tell us that their child gets residential short breaks or the Link Plus service. In contrast parents of only five of the other 62 children on the Compass who attend Downs Park School (all of whom live in Brighton and Hove) tell us that their child gets either of these two services.

Figure 8.8 shows the percentages of children with, on average, the most severe needs (those in Group 1), living in each IDACI quintile of English SOAs, that are reported to be getting a short break service.

Figure 8.8: Receipt of short break services reported for children with severe needs by IDACI quintile

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Parents of just over 40% of the children living in SOAs in the most deprived quintile of English SOAs reported that their child got a short break service, compared to 70% of those in (the average of) the two least deprived quintiles.

In fact for children living in the most deprived SOAs in the city, the proportions reported as getting short break services are even lower. The percentages of Group 1 children living in the SOAs ranking in the most, and next most, deprived decile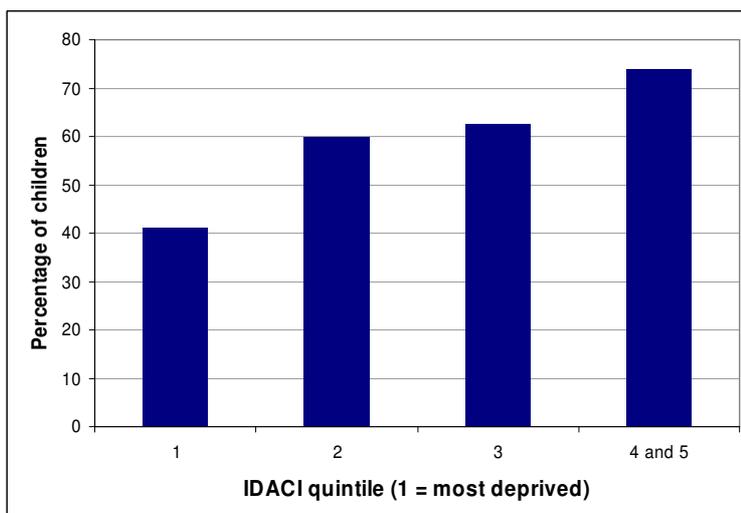 of English SOAs that are recorded as getting a short break service are 32% and 53%, respectively. When SOAs in the second quintile are likewise subdivided into its constituent deciles, the corresponding figures are 55% and 69%. So for the group of children with the greatest needs, the proportion of those who live in SOAs in the most deprived decile that are reported to get a short break service is less than half that of those living in the fourth most deprived decile.

There are 116 children in Group 1 and 164 SOAs in Brighton and Hove. Over half of the SOAs are home to none of these children and another 60+ SOAs are home to just one or two children. Three or four children live in each of the remaining nine SOAs. In two of these nine SOAs no parents of any of the seven children report that they get a short break service. In Figure 8.9 the location of these two SOAs is mapped.

Figure 8.9 shows that these two SOAs are adjacent to one another. Both rank within the most deprived decile of English SOAs for income deprivation affecting children (see figure 6.2). The smaller of these two SOAs is in the Moulsecoomb housing estate and it ranks in the most deprived 5% of English SOAs for income deprivation affecting children. It is the third most deprived SOA for IDACI in the city and 67% of children live in income deprivation (ID 2007). Whereas parents of none of the seven children from Group 1 who live in these two SOAs report receiving any short break services, overall parents of 58% of the 115 Group 1 children living in Brighton and Hove report that they get one or more short break services.

The circumstances of these seven children urgently warrant further investigation. It is possible that some of them do get a short break service but their parents have not reported this. The Compass records of all seven children show that none of their parents say that their child needs any short break services. However, as described earlier, parents/carers often under-report the need for such services.
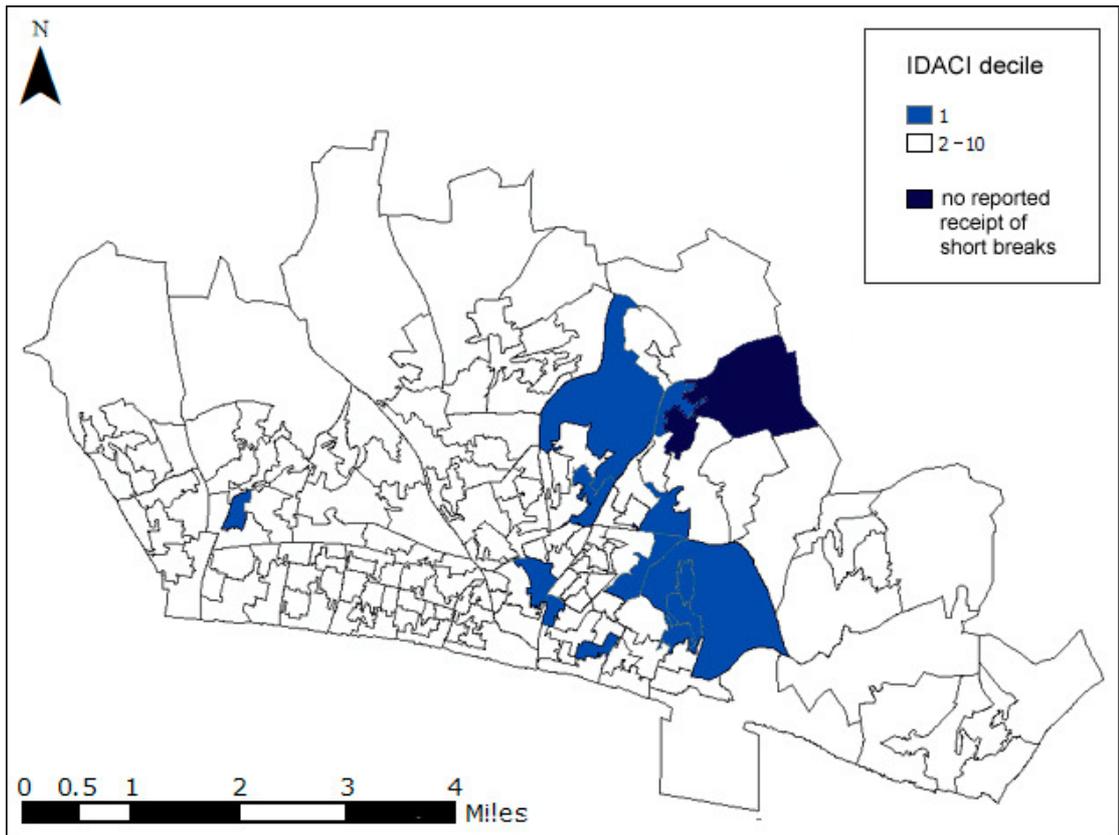

Figure 8.9: The locations of two SOAs where no children with severe needs were reported to receive short break services

Some of the comments parents made about the different types of short break services are summarised in tables 8.7.

Table 8.8: Carers' comments on short break services

Service	Comments
Residential Short Breaks	Affordable respite is needed – I am a 24h carer
	Desperately needed – there are too few respite services and long waiting lists
	We are desperate for this
	We need respite from M but we are not sure if we can get this
	As we are older carers we need that extra help, and respite
Non-residential Short Breaks	We would welcome some respite (not residential) for a few hours at a time
	Would like some kind of babysitting/respite care to have adult time
	We need sitting services
	I am unable to take my child to activities because I am very anxious – we need respite even for an hour
Link Plus	Waiting to hear
	Still waiting to start
	Not enough
	Fantastic – my daughter really looks forward to this and I don't know what she would do without it

As with leisure services, most of comments parents made about short break services related to what they felt was still needed. However, some services were praised, including Outreach and Link Plus.

Direct Payments

The Compass knows of 40 families in the city who use Direct Payments (DP). The following chart (Figure 8.10) shows the percentages of children on the Compass whose parents tell us they use or need Direct Payments, by deprivation quintile.

Although based on data from relatively few families, these findings are compatible with those families living in the more deprived areas being much less likely to receive Direct Payments. Interestingly however, the proportion of parents who say they need Direct Payments is highest in the most deprived quintile and is more than double the proportion who say they use Direct Payments. However, receipt of Direct Payments is over four times more likely amongst families living in the two least deprived quintiles of English SOAs than those living in the most deprived quintile.
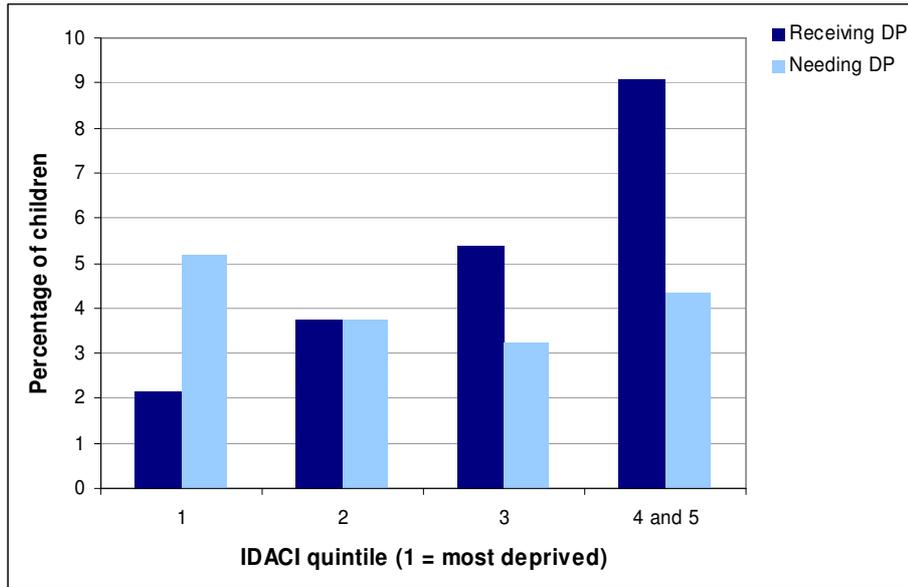
Figure 8.10: Receipt and need of Direct Payments reported for children on the Compass by IDACI quintile

8.4 Conclusions

The main observations were:

- Parents of the majority of children in the group with the most severe needs said that their child got short break services, but few other children, including those with quite complex/severe needs, apparently got them.

- Parents of a substantial proportion of children in the group with the most severe needs, but much lower proportions of children with quite complex/severe needs, reported that their children attended after school and holiday playschemes.

- Fewer of the parents of children with the most extensive needs living in the more deprived areas of the city reported that their children got a short break service or attended holiday playschemes, than those living in the less deprived areas.

- Fewer parents of children living in the more deprived areas of the city reported using Direct Payments than those living in the less deprived areas. But more reported needing, but not getting, this service.

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- All three foster parents of children at Downs Park School reported that the children they looked after got services that offered their child some form of short breaks away from their home, compared to only one in twelve of the other parents of children at this school.

A major strength of the analysis presented in this chapter is that it was performed on children grouped broadly according to the extent of their special needs. Considerable differences in the profiles of parentally reported receipt of, and need for, leisure and short break services were observed for children with different severity of support needs and for children living in more or less deprived areas. However, a major weakness of this reductionist style of analysis was that it was applied to a sample of only about 1,000 children. So some of the constituent groups are very small and little confidence can be placed in results involving small numbers of children. For example, foster parents of all three looked after children at Downs Park School reported that their child got either residential respite or the Link Plus service, compared to only five of the parents of the other 62 children. But it would be precipitous to assume that looked after children preferentially receive short break services without gathering data on more looked after children.

Another major limitation stems from the fact that the Compass is a voluntary register. As already discussed, the analysis presented in Figure 8.1 might be taken to imply that the intake of special schools is biased towards children living in less deprived areas, and that the bias is strongest in special schools for children with the most extensive needs. But this bias could also have arisen through the preferential uptake of Compass registration by families with children with the least severe needs living in relatively deprived conditions, who, overall, are likely to reap most benefit from the leisure concessions offered by the Compass card.

Generally parents fill in the Compass registration form without advice or assistance from health, education or social care professionals. This increases the likelihood of misreporting of service receipt (and need), and this is clearly a further major limitation on this study. For example, the data collected suggest

that children from families living in the most deprived areas are more likely to miss out on holiday playscheme places and short break services. However it is possible that they are as likely to receive these services as children from less deprived areas, but their parents are simply less likely to record receipt of these services on the Compass registration form.

Perhaps therefore the greatest value of the analyses presented in this chapter is to stimulate ideas for further studies, including on alternative datasets, that can be used refute or confirm the generality of these observations. All schools collect data that could, for example, be used to determine an area deprivation profile for pupils attending each school (or type of school), analogous to the one shown in Figure 8.1. Child health systems record information on children's medical diagnoses and place of residence. If the (anonymised) findings from these datasets were publicly reported by SOA, it should be possible to establish whether special school places were allocated broadly according to need or whether there was a bias towards uptake of special school places by children from families living in less deprived areas.

In the case of the seven children with severe needs who live in two adjacent and highly deprived SOAs, but apparently get no short break services, the simple expedient of the Compass co-ordinator inviting their parents to take part in telephone or face-to-face interviews could clarify the situation. More generally, Amaze should consider instigating some kind of quality control monitoring on the parental reporting of service receipt and need.

This study highlights the potential importance of local authorities not simply monitoring the overall uptake of services by disabled children but additionally finding out whether the services are being delivered equitably within the locality.

A smart card system could, in theory at least, provide a better way than Compass registration to monitor receipt of services. The CYPT could issue personalised smart cards to families with disabled children that would be swiped across service-specific card readers each time a child accessed the service. Provided cards were personalised (and records contained, or could be linked to,

demographic data on the child), the CYPT could collate, monitor and analyse data on the receipt of short break services. In practice it would be crucial that the card and reader were always available for recording service receipt and that a data analyst was employed to collate and analyse the data. They could then establish whether disabled children living in more deprived areas were as likely to get services as those in less deprived areas. They could also determine what levels of support they were providing to families with children with very significant (but not the most severe) needs.

If other local authorities adopted similar systems for monitoring and analysing service receipt the problems associated with analysing small numbers could possibly be mitigated by grouping the data at county or regional level.

The comments that parents made on their children's Compass forms about leisure activities added important context to the quantitative analysis presented here. For example, parents of very few teenage children, other than those in Group 1, reported that their children attended after school and holiday playschemes. Their comments underscored that there was a gap here in services, with mainstream schemes generally only catering for children up to early teens, thus leaving their teenage children either unsupported and vulnerable or isolated.

Several comments highlighted the dangers of making conclusions about individuals based on the overall demographics of areas. (This phenomenon is termed ecological fallacy.) For example, although the majority of parents who commented on not being able to afford activities lived in SOAs ranking in the top IDACI quintile, some lived in the lowest two quintiles.

The finding that the majority of parents the Compass knows of who are receiving Direct Payments live in the less deprived areas of the city merits further investigation. Direct Payments (user-controlled purchasing of social care) have moved to the heart of government's drive for user choice, but implementation has been disappointing. There has been considerable interest from academics and disability activists in understanding why uptake has been so low and uneven within the UK (Ridell *et al.*, 2005). Vernon (2002) noted that people from black

and ethnic minority groups exhibited especially low levels of engagement with direct payments and they were disproportionately located in deprived areas. More recently Fernandez *et al.* (2007), using the local authority as their unit of analysis, found that, whilst a complex interplay of underlying processes are involved, Direct Payments policy implementation activity was not randomly distributed, but was being systematically shaped by the features of localities. The higher the proportion of the local population providing informal care, the lower the take-up of direct payments was by people with physical disabilities and people who used mental health services. The take-up of Direct Payments for people with physical disabilities was higher in less deprived areas but the opposite was true for people who used mental health services. In the case of people with physical and learning disabilities it was greater in areas with lower population density. Their results also revealed a strong negative relationship between the per capita number of recipients of Direct Payments and the size of the average Direct Payment package. These findings underscore that there are various inequities in the take-up of Direct Payments, including an influence of locale. But, to our knowledge, no small area analyses (for example, at ward or SOA level) of take-up of Direct Payments have yet been reported. If, as these preliminary findings suggest, Direct Payments are much less accessible to families living in more deprived areas *within* a locale, then this constitutes another major inequity that should be taken into account when considering the potential value of this scheme. Amaze is already acting on this preliminary finding and, as a front-line voluntary organisation involved in supporting implementation, it is beginning to explore with current users, and with parents/carers whose children could potentially benefit from Direct Payments, how (area) deprivation impacts on their willingness and ability to take up Direct Payments.

Chapter 9

Conclusions

Introduction

This thesis provides a response to recent calls from central government that there is a need to more effectively record and monitor local populations of disabled children. In the first section of this chapter the academic contributions of this work are discussed and in the second section the potential impact of the findings on the processes used to address the needs of local disabled children are discussed.

9.1   Academic contributions of this thesis

One of the contributions this thesis makes to academic knowledge is that it highlights the importance of geographic analyses at the small area level, as opposed to sub-regional or larger geographies, as a first step to understanding the geographical processes that give rise to inequities in the receipt of services by individuals. This research has focused on disabled children living within a largely urban, and geographically small, local authority. It strongly suggests that resources are unequally apportioned to children and families living in more and less deprived areas and neighbourhoods. If the study area had been geographically large or had been made up of a mixture of urban and rural areas, geographical variations in the levels of resourcing of services, and rural isolation, would potentially have impacted on the availability of services. For example, such factors have confounded studies aimed at determining whether the prevalence of autism varies geographically. In a study of the prevalence of ASCs amongst children aged 5-11 in Cambridgeshire, Scott *et al*. (2002) found wide variations between the Peterborough area (27 per 10,000), the Cambridge area

(65 per 10,000) and the Huntingdon area (84 per 10,000). They concluded that the differences were likely due to differences in awareness of ASC amongst professionals, or variations in service and funding availability in different parts of Cambridgeshire, rather than in actual geographic variations in prevalence. However, in contrast to Cambridgeshire, in Brighton and Hove services for disabled children are centrally allocated and, in some cases, individual professionals deliver their service across the whole local authority. So studies in locales such as this open the way for analysing how differential diagnosis and differences in uptake of services are related to area deprivation and neighbourhood.

Much of what is known about the determinants of access to health care comes from studies undertaken at a large scale, such as between cities, regions or countries. Exceptionally, Law *et al.* (2005) looked at how place impacted on access and use of health care in four distinct neighbourhoods within Hamilton, New Zealand, a city similar in size to Brighton and Hove. Contrary to what was expected in terms of resident to physician ratio and geographical distance to services, they found higher levels of use of health care services in the study neighbourhood with the highest socio-economic profile and highest reported unmet needs in the one with the lowest socio-economic profile. The findings of this thesis, too, are that residents of the neighbourhood with the lower socio-economic profile experienced more limited access to services. Like MacIntyre *et al.* (2002), these authors concluded that a fuller understanding of how place impacts on utilisation of health services will require more nuanced studies at small area level, that aim to unpick the relative importance and interactions between composition (the properties of individuals), context (the characteristics of the place and space they inhabit) and collective (the nature of the social relationships – formal and informal – in which the individuals engage within their context). From the perspective of a front-line organisation such as Amaze, these findings underscore that local authorities do need to measure and monitor the need for, and uptake of, services geographically (that is, at small area level), otherwise they have no way of knowing whether their services are reaching all those in need rather than only those best resourced to access the service.

Related to the importance of micro-geographical studies, and of relevance beyond the topic of childhood disability, are the findings highlighted in this work, that:

- there is much greater heterogeneity in numbers of children (and older people) per SOA than in total numbers of people, and
- in some SOAs (in Brighton and Hove) the proportions of children and older people living in income deprivation are markedly different.

Unless planners/service providers take both these kinds of heterogeneity into account, they are unlikely to be able to make the best use of SOA geography and the indices of deprivation to identify and respond to service need at small areas. Unfortunately, however, it appears that there are substantial barriers to service planners using these tools effectively. Academic geographers devised the SOA geography and provided the theoretical basis for the ID exercises. They advocate that SOAs, the new geographical units, should be used rather than wards (which have more subjectively generated boundaries and higher and more varied numbers of residents). But service planners often do not understand the subtleties that underlie the apparent simplicity of SOA geography. Few service planners appreciate that SOAs are much more heterogenous in terms of numbers of children (and older people) than in overall numbers of residents. And most struggle with the alphanumeric (geographically featureless) SOA naming system, to the extent that they cannot match named SOAs to their map locations. But academic geographers are actively discouraging the development of, for example, a ward-based naming system for SOAs (partly on the grounds that some ward boundaries may change in the future), even though the ward is the geographical unit that most service planners can relate to. It is possible that their lack of appreciation of the conceptual and practical difficulties SOA geography presents to service planners is, in part, a result of the antipathy of academic geographers to policy-relevant research.

According to Mohan (1996), by the late 20th century British academic geography was contributing little to debates on crucial contemporary issues such as the collapse of community, the future of the welfare state and social polarisation. He

felt that when researchers did not actively engage with the oppressed groups they were researching - either in some practical way, or with their politics - that they were practising systematised selfishness. He went so far as to suggest that unapplied knowledge was knowledge shorn of meaning. Prominent human geographers joined the debate; Martin (2001:189) noted that most of the blame for geography's irrelevance lay within the discipline:

> "The fundamental problem, I argue, is that for a variety of reasons much contemporary social and economic geography research renders it of little practical relevance for policy."

Dorling and Shaw (2002) argued that geographers' failure to contribute to policy formation was because the fashion for 'better conceptualization' within human geography (Massey, 2001) had led to a disdain within sections of geography for the kind of work that policy-makers listen to. Moreover, the language and expression of the 'reconceptualizing geographers' had often become an élitist jargon that policy makers did not understand or consider relevant. When Davey Smith *et al*. (2001) compiled a list of academics who had influenced policy around poverty, inequality and health over the last two centuries, they struggled to identify any geographers. Dorling and Shaw (2002) therefore concluded that most geographers were concerned with thinking about (and understanding and explaining) spatial relationships, not with changing them.

In the last decade UK policy on the provision of services to children and young people, across education, health, social care and recreation has undergone a sea change. There have been many initiatives under titles such as 'Supporting Families', 'Every Child Matters' and 'Youth Matters', alongside legislation such as the Children Act 2004, the Child Care Bill and the Education white paper, and a new National Framework for child and maternal health. Some of the key trends include:
- The increased importance of the child's 'voice' in policy development.
- More child-centred (personalised) policies.
- Parents as loci of social change and control.

- Children as loci of social investment (the adults of the future).
- Views of children as victims or villains.
- Avowed commitment to evidence-based policies.

On the face of it, this is an arena in which children's geographers would be well-placed to contribute. Fiona Smith has, for the last decade, been involved in researching childcare. She has explored with children how they would like to be involved in the development of childcare services. New Labour committed to ending child poverty by 2020 and saw getting adults back into work as the major route out of poverty; but many mothers cannot work unless they can find accessible and affordable childcare. Smith's work has informed local and national policy, yet prominent geographers have asked her what it has to do with geography (Smith, 2004). To some extent, Children's Geographies seems so focused on the personal that it has lost sight of, or interest in, the broader context. Smith (2004) argues that unless geographers do get involved, key findings, that they are particularly well situated to make, and that can improve children's lives, will be missed.

Another major finding of this work is not just that disabled children are more likely to live in more deprived families and places, but that they are much more likely to do so. The proportions of children on the Compass were five times higher in the most income-deprived SOAs of Brighton and Hove than in the least income-deprived SOAs. Few children's geographers who study 'other' childhoods use or engage with quantitative methods. However these findings highlight that it is important for academic researchers in Children's Geographies and in Disability Studies to engage with quantitative studies. If researchers lack the motivation, or do not practise the skills, to critically appraise quantitative studies, they may severely limit the sphere of their own investigations. In this case, if researchers do not appreciate that the proportions of disabled children are considerably greater in economically deprived areas or neighbourhoods, they may not prioritise giving voice to parents and disabled children affected by income or neighbourhood deprivation. Some of the issues and solutions for the minority of disabled children, who live in less-deprived families and

neighbourhoods, may be very different to those for the majority. So in-depth qualitative studies with the former families may, at best, result in a very partial knowledge and tangential findings. At worst, they could prove misleading, since balanced representation is needed to gain a full understanding of the underlying (geographic) processes. Such objectivity is an important practical and philosophical goal for academic researchers and a valuable preface to the formulation of effective policies.

Even if qualitative researchers wish to target participants from particular groups, in practice they can often only recruit from a limited range of people; and, in general, the more socially excluded people are less likely to participate in academic studies (for example, see Curtis *et al*., 2004). However, quantitative studies such as this one can provide strong pointers to which groups of parents and disabled children it might be particularly pertinent for children's geographers to work with in order to explore the complete range of issues families with disabled children may encounter. It should also be possible, following on from the current study, to identify individuals from selected groups and invite them to participate in in-depth qualitative studies. In this way skilled qualitative researchers could be linked with participants from particular cohorts of families.

One way in which this thesis informs policy is by providing a fuller and broader evidence base on childhood disability in Brighton and Hove. In general, policy makers do tend to respond to 'numbers' (for example, see Valentine, 2006). Some of the findings of this thesis were presented to Brighton and Hove's Children's Disability Service in the winter of 2008/09. Local planners of short break services have responded by modifying existing services, or introducing new services, to fill gaps identified for particular groups of disabled children through analysis of the Compass dataset (Brighton and Hove City Council, 2009). In this case, quantitative analysis has therefore proved emancipatory, in that more families with disabled children are benefiting from short break services, their views are informing the development of services that better suit their needs, and they should have good opportunities to influence best practice provision in the future.

Analysis of the multivariate data collected through the Compass provided a demonstration that some disabled children in Brighton and Hove experience multiple disadvantages and that those living in the most deprived areas were more likely to experience more disadvantages than others. As discussed in Chapter 3, the IMD does not measure multiple deprivation *per se*, and there are few quantitative studies that measure more than one aspect of deprivation at a time for families with disabled children. Demonstrating to service planners that disabled children living in the most deprived neighbourhoods of Brighton and Hove experienced a greater range of disadvantages and were unlikely to have the kinds of resources to facilitate their inclusion (in, for example, leisure activities), was another important message. Many local children's services providers had not considered the large differences in life circumstances experienced by disabled children living in different parts of the city, most likely reflecting a more general ignorance of disability. and of life in East Brighton's social housing estates, amongst local residents.

Children with learning difficulties make up the majority of those on the Compass. Comments parents made to the Compass highlighted a general unawareness of invisible childhood disabilities, both among members of the public, and also amongst some professionals who work with children in Brighton and Hove. There is also a lack of appreciation of the extent of economic and neighbourhood deprivation and social exclusion many disabled children experience. At the outset, the disability movement, and Disability Studies, was mainly the prerogative of white middle class men with physical disabilities. The social model of disability, the 'big idea' of the disability movement, challenges the traditional view of disability as a medical tragedy, and replaces it with a view of disability as a social oppression. There is little doubt that social model principles were pivotal to the disability movement's ability to leverage change, for example in improving the accessibility of the built environment and in the de-institutionalisation of disabled people. But the movement continued to uphold the model as a solution for all disabled people's problems after concerns had been raised that it could not fully explain the exclusion of people with learning disabilities, people with mental health difficulties and people with chronic pain. During this time, research in Disability Studies focused on physically disabled

people and the disability movement excluded people with intellectual disabilities. Perhaps the reason that so few people have any conception of hidden disability, and that the majority think of access only in terms of wheelchairs, hearing loops, and Braille, is, in part, a legacy of academic intransigence regarding the social model of disability.

It was only in the late 1990s that any coherence to the sub-field of the Geographies of Intellectual Disability began to take shape. For example, 1998 marks the first time that the (94th) Annual Meeting of the Association of American Geographers included a session on this topic. Three years later Hall and Kearns (2001) made a serious attempt to rectify the omission of intellectually disabled people from Geographies of Disability. They noted that the geographies of intellectually disabled people were largely ignored and that the social model of disability largely excluded the mind and mental differences, yet apparently spoke for all disabled people. They also highlighted how the de-institutionalisation of learning disabled people was rendering them even more invisible, both on the streets and as a focus for study. Moreover, although many of the people with intellectual disabilities that they interviewed lived and worked in the community, their research revealed that most did not feel part of it. In a study of how place was experienced amongst a group of intellectually disabled people in Toronto, Laws and Radford (1998: 80), demonstrated remarkable insight, when they argued that neglect of the geographies of intellectual disabilities could have a serious material effect on people's everyday lives because "only a slender body of knowledge has existed on which to base the implementation of community-based policies". Even so, seven years later Philo and Metzel (2005), reflecting on progress in understanding the geographies of intellectual disability, concluded that the spatial epidemiology of intellectual disability was still virtually unexplored in the geographical literature.

Hall (2005) researched the views of people with intellectual disabilities on what everyday places they felt most and least included in. Ironically, it was in the 'exclusionary' spaces (such as the sheltered workplace, and the care home) that they often felt most included and in the 'inclusionary' spaces (such as the street, and the workplace) that they often felt most excluded (friendless and valueless).

Holt (2004a) has similarly noted that practice that is labelled 'inclusive' can actually be exclusionary. For example, disabled children in mainstream schools were excluded from Physical Education lessons (that they particularly enjoyed) in order to attend therapy sessions; some children with physical disabilities were excluded from the playground for health-related reasons. Perhaps this is an important vantage point from which to begin considering the topic of the bullying and exclusion from school of disabled children.

An important finding in this thesis is that the exclusion from school of disabled children is extremely common and that, in Brighton and Hove, it is most frequent for children living in the most deprived neighbourhoods. In more deprived areas of the city, children on the Compass are also more likely to be bullied or to be involved in bullying others. The schools' data on exclusions that is reported annually by the ONS has only recently been collected and presented in a way that reveals the high prevalence of exclusion from school of children with SEN (discussed in Chapter 7). Only in the most recent ONS report has any attempt to factor in area deprivation been made. It did not reveal a major area deprivation effect, but (as school rather than pupil address was used to allocate SOA) the methodology was unnecessarily crude (ONS, 2009).

Findings from studies such as described here, on the neighbourhood effect and high incidence of school exclusion of disabled children, do merit wide dissemination, otherwise they will not be taken into account for policy formulation. For example, the Institute for Public Policy Research, an influential think tank in British politics, published a report entitled "Make Me a Criminal: Preventing youth crime" in which the authors identified that pupils who had been expelled from school were the most 'at risk' of becoming offenders (Margo and Stevens, 2008). But this report lacked any evidence about the geography of exclusion and the extent to which children with SEN and disabilities were affected. Although it recommended targeting interventions to the geographically most deprived areas there was no consideration of SEN and disability (or, therefore, how this might intersect with neighbourhood). If an extremely high incidence of school exclusion of children with SEN living in the poorest neighbourhoods had been implicated, recommendations could have been much

more specifically targeted at SEN-related issues, including the role of schools in the (early) identification of children with SEN (which, for some families, is a prerequisite for educational, health and social care interventions), differentiated delivery of the school curriculum, and whole school approaches to bullying. They might also have included the referral of families to services able to empower parents to provide practical support to their children, including assistance to claim DLA, and parenting courses tailored to cover issues of particular importance to parents of disabled children, such as behaviour management.

A recent report from the UK charity Mencap, that supports people with learning disabilities, found that nearly all children with a learning disability were bullied (Mencap, 2007). It is well documented that high proportions of young offenders and older prisoners have learning disabilities (for example, see Talbot, 2008). Another reason why it is important to disseminate the findings that pupils with SEN are eight times more likely to be excluded from school than other pupils relates to the numerous reports of how invisible disabilities (such as learning disabilities, mental health disorders and ASCs) are rarely comprehended or acknowledged by the criminal justice system and how, during the trial and sentencing process, anxious young people with learning and communication difficulties are particularly disadvantaged.

Another finding of note in this thesis was that the majority of families with disabled children who were in receipt of Direct Payments lived in less-deprived SOAs, whereas the majority of those who felt they needed Direct Payments lived in more-deprived SOAs. Researchers in Disability Studies have tended to focus on the uneven uptake of Direct Payments across the regions and countries of the UK (for example, see Priestley *et al.*, 2007). However, Dawson (2000), studying take up of Direct Payments across Norfolk, noted that there might be a tendency for disabled people living in sparsely populated rural areas not to take up Direct Payments. Leece and Leece (2006) investigated whether the uneven take up of Direct Payments might reflect class inequality in society. They analysed the circumstances of all adult service users who had been financially assessed in one local authority. Although those taking up Direct Payments were younger than

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those using traditional services, no significant difference in their levels of financial wealth were found. However, Ellis (2007), using semi-structured observations of social workers in one local authority, found that policy and operational ambiguity surrounding Direct Payments, coupled with an shortage of resources, created both the conditions and imperatives for them to ration access to Direct Payments and practise 'street-level bureaucracy' (Lipsky, 1980). Although the findings of uneven geographies of receipt of Direct Payments reported here must be considered tentative, as they are based on small numbers and a voluntary registration dataset, this is a crucial area for further research, of importance to academia and to policy and practice.

9.2   How the findings could contribute to good practice

This thesis can be considered as an exploratory step towards finding more robust ways of reporting childhood disability and the circumstances of disabled children. There are a number of lessons that can be drawn from it that might aid local authorities in better understanding the nature and magnitude of their population of disabled children and their service needs.

It is important to note that because the Compass is a voluntary registration database, none of the analyses presented here can constitute evidence of inequity in service receipt by families with disabled children in Brighton and Hove. However, it became apparent during the course of this work that there is no local (or national) dataset that represents all disabled children. As discussed in Chapter 4, the receipt of Disability Living Allowance is a poor proxy indicator for childhood disability, because it is estimated that about half of disabled children do not receive it and receipt is biased towards less deprived families. Having a statement of SEN is also a poor proxy indicator of disability since many disabled children do not have statements of SEN and some children with statements are not disabled. Interestingly, however, Mooney *et al*. (2008) have assumed that the number of children with statements of SEN represents the upper bounds to the numbers of disabled children.

A radical approach to ensuring that local authorities can count the numbers of disabled children is to reform the way in which DLA is administered. This would require much more than simply reducing the bureaucracy surrounding the process of claiming this benefit. It would also require health and social care professionals to inform all parents of disabled children of the existence of this benefit and to practise effective early identification of all children with disabilities. Clearly, this approach could also impact on the uneven identification of children with SEN in different schools. To be most useful for service planners, DLA datasets would ideally include information on the child's age and the type and severity of their condition, as well as place (SOA) of residence.

Unless or until disability benefits reform occurs, the work presented in Section 5 of Chapter 5 constitutes a simple way for any local authority to map the numbers of children living in income deprivation, making use of readily available datasets (the most recent mid-year population estimates and the current IDACI dataset). Ideally, every local authority would appoint a children's data officer/champion, with a remit to collate and analyse all data available on local children, and present the findings. Such mapping, which would be part of the children's data officer's role, would help provide a basis for considering how to equitably distribute resources (services) within the local authority.

To determine whether a service is preferentially being used by children from certain areas, it is important to record the geographic take up of services within the local authority and compare this to the geographic distribution of the child population. Otherwise there is no way of knowing whether (or to what extent) children living in the poorest areas and neighbourhoods are preferentially excluded from taking up the service. One approach would be to electronically record service usage across all (disabled) children's services, for example using a smart card or similar technology, and to analyse service usage by place of residence and type of disability. The children's data officer would be therefore be able to monitor the micro-geographies of service usage by disabled children.

The analysis of data collected on local disabled children could very usefully be complemented by (geographic) analysis of the extensive local data already being

collected on individual children within schools by local Education departments. Such analyses could reveal whether there is a geographical bias in the proportions of children with identified SEN in more and less deprived neighbourhoods and areas of Brighton and Hove, whether children with statements of SEN who attend special schools are equally represented from different areas of the city, and whether exclusion from school is primarily an issue for children with SEN, particularly those living in the East Brighton housing estates.

There is a drive within the NHS to make more health data publicly accessible. Information on every child is recorded on each PCT's Child Health System. However, some of the PCT's registered population live beyond the geographical boundary of the local authority and, for some variables, coding criteria can differ from PCT to PCT. At present, small area-level analyses of the data from Child Health Systems are rarely made publicly accessible. Nevertheless, some information, most notably on low birth weight, which is a strong predictor of future disability, could usefully be extracted and made publicly accessible. Then local authorities could access (longitudinal) information on the percentage of low birth weight infants born in each SOA.

A transparent offer detailing the nature and level of support available to families with disabled children might help reduce inequities in service receipt between different families and different neighbourhoods. But the offer needs to be accompanied by proactive and targeted promotion/social marketing, otherwise the most marginalised families may not recognise that their children have additional needs and/or that they are entitled to support. A specific recommendation following from this work would be to target information and advice should to families living in the East Brighton housing estates.

The more socially excluded families living in deprived neighbourhoods can experience major barriers to obtaining information. Amaze's DLA Project Co-ordinator, Lizzie Batten (personal communication), notes that families living in deprived neighbourhoods will encounter more disabled people and may therefore be more accepting of embodied difference, and consequently less likely to

recognise their child has additional needs or to consider them 'disabled', than those living elsewhere. The stigma associated with living in particular places can impact on the way some professionals treat families. Interestingly, when Davidson *et al*. (2008) examined how people living in more and less deprived neighbourhoods expressed their experiences of inequality, those from the more deprived areas recognised the contribution of contextual factors to health inequalities, whereas those from better off areas generally believed that health inequalities could be attributed to poor lifestyle behaviour. However, people from the less deprived neighbourhoods who had worked with people from more deprived areas, or had direct experience of deprivation, did recognise the importance of contextual factors. In addition to neighbourhood effects, disabled people, and families with disabled children, still commonly experience discrimination in the UK (for example, see Miller *et al.*, 2006). Therefore local service planners and providers should attend well-crafted inequality and disability awareness training so that they are alerted to the range of local neighbourhood effects and can reflect on how disability discrimination might intersect with these. If the inequality and disability awareness training incorporated some direct working with families with disabled children, who live in the East Brighton housing estates, in their everyday environments, more professionals might develop an appreciation of the importance of contextual factors.

There is a burgeoning personal choice agenda across health and social care. Ironically, however, there is a danger that increasing personal choice within (for example) the NHS will result in widening (health) inequalities. Tudor Hart (1971) outlined the 'inverse care law', which described how people in deprived areas tended to have greater health needs but were less likely to access good health care. There is much empirical evidence to support this, particularly when analyses are carried out for clearly defined condition–treatment pairs. For example, Payne and Saul (1997) found that symptoms of angina were more prevalent in less affluent electoral wards but people living in deprived wards were less likely to receive coronary artery revascularisation. Shaw and Dorling (2004) examined 2001 Census data on medical care, informal care-giving and health status. The data provided evidence that the inverse care law operated in

England and Wales: medical care was provided inversely in proportion to need, with medical professionals as a group achieving a south (eastern) bias despite the majority of their most needy client group living in the North. Importantly, however, they also found that informal care was provided in direct proportion to need: people in areas of higher need received disproportionately more informal care than professional medical care.

As well as a greater availability of services, residents of less deprived areas, are often better equipped to find and assimilate the relevant information and to negotiate successfully with healthcare professionals. In a London pilot, when NHS patients were provided with advisers who could give them information, explain the process, and organise free transport to the service of choice, the process became fairer (Guardian, 2005). It is therefore crucial to find ways of helping the most disadvantaged families access information and to empower them to make use of it to get suitable services. The Direct Payments system is an example of a scheme that was developed in response to disability rights campaigns rather than being initially imposed by government. However data presented in this thesis very strongly suggests that it is much less accessible to local families with disabled children living in the more deprived areas of the city.

Unless service providers can interpret quantitative data, displayed in tables graphs, charts and maps, they will not be able to understand how much more disadvantaged (disabled) children living in deprived areas of the city, and East Brighton housing estates in particular, are. Unless they can gain a better understanding of the ID exercises and the new SOA geography they will not be able to use geographical data effectively in service planning. Gaining the skills to interpret such data could be considered as an important extension of inequalities awareness training.

Houghton (2005) has noted that over the last 50 years the Irish State has reduced the number of disease/mortality maps it makes publicly accessible. He considers this tantamount to 'hiding the evidence' on the geography of health inequalities and he entreats researchers in health inequalities to disseminate their findings in

and beyond the academic arena. Service providers in Brighton and Hove responded with interest and some surprise to ward and SOA level maps dispalying publicly accessible data on local children, as well as to maps displaying Compass data. This suggested that they do not often see such maps. The importance of small area mapping has been highlighted in this thesis and elsewhere (for example, see Foley *et al*., 2005), but in many local authorities, including Brighton and Hove, there still appears to be a mismatch between the ability to produce such maps and the processes required to make them accessible to service providers and planners.

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Appendix 3.1: Compass Registration Form

The Compass

The Compass collects information about children and young people, aged up to their 20th birthday, who live or go to school in Brighton and Hove, or are 'looked after' by children's services, and have special needs or health conditions that significantly impact on their everyday lives. This is to help education, health, voluntary organisations and social care to look at their current services and work together to plan future services for children. Registration on The Compass is voluntary, but the more people who join, the greater its impact will be.

The child's parent, or a carer with parental responsibility, should complete this form and in some cases your child could also be involved. For children who are subject to a care order, their social worker should be consulted and sign the form as well (see back page). **If you aren't sure whether your child should be registered, or there is anything you don't understand, please call AMAZE on (01273) 772289.** You are free to choose which questions you answer. Please fill in a separate form for each disabled child in your family. Young people aged 16 or over are welcome to complete their own form. Please return the form (no stamp needed) to: AMAZE, FREEPOST SEA14216, Brighton, BN1 3ZZ.

Your details are then entered into The Compass database. If you wish, we will send you a copy of the information. You'll receive a Compass Card, our termly newsletter, and, occasionally, information about local services. We ask you to update your information every two years.

Your Child's Details

First Name:_____ Family Name or Surname:_____

Address:_____ Date of Birth:_____
_____ Sex: Male / Female
_____
Postcode:_____ Tel No:_____

Your child's NHS Number:_____
(this is on your child's medical card or in their red book)

Your child's GP and practice:_____

Parent or Carer's Details

Title:_____ First Name:_____ Family Name or Surname:_____

Address if different from above:_____
_____
_____
Postcode:_____ Tel No:_____

Your email address:_____
I prefer to receive the AMAZE newsletter **by email / by post**

Your relationship to child:_____

Do any other adults have a major share in the care of your child? Yes / No
Do you usually get a complete night's sleep? Yes / No
Do you or another main carer have a disability or long term health problem? Yes / No

Brothers and Sisters

Does your child have any brothers and sisters? Yes / No   If so, how many? ____
Do any of them have special needs? Yes / No   If so, how many? ____
Do any of them share in the care of your child? Yes / No / Not Applicable

amaze

Please describe your child's diagnosis/difficulties

_____
_____
_____
_____
_____

Please tell us more about your child's needs by ticking ONE box per question:

1 Does your child have a learning difficulty?
- ☐ No
- ☐ Mild
- ☐ Specific, such as dyslexia or dyspraxia
- ☐ Moderate
- ☐ Severe
- ☐ Profound

2 Are your child's communication skills appropriate for his/her age?
- ☐ Yes
- ☐ Has limited understanding and/or difficulties expressing him/herself
- ☐ Relies on gestures, aids or other people to express his/her needs

3 Does your child have any visual problems?
- ☐ No
- ☐ Mild - for example, cannot see well enough to recognise a friend across the road
- ☐ Moderate
- ☐ Severe - for example, cannot tell by the light where the windows are
- ☐ He/she is registered blind

4 Does your child have any hearing problems?
- ☐ No
- ☐ Mild - for example, doesn't hear if his/her name is called in the street
- ☐ Moderate - hearing could be improved by a hearing aid
- ☐ Severe - is profoundly or totally deaf

5 Does your child have challenging behaviour?
- ☐ No
- ☐ Mild - for example, is often miserable, afraid, or worried about different things
- ☐ Moderate
- ☐ Severe - for example, is aggressive, is destructive, often shouts, hurts him/herself

6 Does your child have any mobility Problems for his/her age?
- ☐ No - fully mobile
- ☐ Moderate - needs help/walking aids or tires very quickly
- ☐ Severe mobility problems

7 What personal care does your child require, for example, with washing, dressing feeding?
- ☐ Generally age-appropriate
- ☐ Needs help/prompts
- ☐ Is dependent on others

8 Are your child's toileting skills appropriate for his/her age?
- ☐ Yes
- ☐ Needs help/prompts
- ☐ Is incontinent at night
- ☐ Is incontinent

Does your child have a condition that requires medical treatment or intervention every day, such as daily medication, physiotherapy, or need of suction machine? Yes / No

If so, who provides this care:_____

And have they received enough training/help? Yes / No / Not Applicable

How many days has your child spent in hospital in the last year?   0 / 1-5 / 6-10 / 11-15 / 16-20 / 21+

How many medical appointments have they had in the last year?   0 / 1-5 / 6-10 / 11-15 / 16-20 / 21+

If your child has a GP, do they have a good grasp of your child's needs? Yes / No / Not Applicable

Is your child registered with a dentist? Yes / No

If yes, are you satisfied with their treatment Yes / No

Does your child need constant supervision? Yes / No

Does your child receive Disability Living Allowance? Yes / No

Do you think your child's housing is adequate for their needs? Yes / No

Education

What is the name of your child's nursery, school (and special unit),
or college?_____

If it is outside Brighton and Hove, where is it?_____

Does your child board there? Yes / No

Does your child have a statement of Special Educational Needs (SEN)? Yes / No
If not, are they getting support through School Action Plus or Early Years Action Plus? Yes / No

Has your child been excluded from school in the last year? No / At Risk / Temporary Exclusion /
Permanent Exclusion
Or informally excluded (eg, you've been asked to collect them before school ends)? Yes / No

Has your child ever experienced bullying at school? Yes / No / Don't Know
And out of school? Yes / No / Don't Know
Because of their special needs, have they been involved in bullying others? Yes / No / Don't Know

Services

**By telling us about the services you get and need, you can help influence how services
develop in Brighton & Hove.**

Please tell us which of these services you've received during the last year by ticking the "receiving" box.
Please tell us which ones you don't receive, but feel your child would benefit from, by ticking the
"needed" box. Please do this even if you've been refused the service, or know there's a long waiting list.
It's OK to tick both boxes if you are receiving a service but feel you need more of it.
For more information about any service please call AMAZE or refer to our booklet 'Through the Maze'.

receiving	needed	**Health**
☐	☐	Hospital Paediatrician
☐	☐	Community Paediatrician—such as a paediatrician at the Seaside View Child Development Centre
☐	☐	Community Paediatric Nurse—such as the Home Care Team or a School Nurse for Children with Disabilities
☐	☐	SSSH - Specialist Sitting Services at Home (for children with life-threatening conditions)
☐	☐	Specialist Health Visitor
☐	☐	Family Health Visitor
☐	☐	Occupational Therapy
☐	☐	Physiotherapy
☐	☐	Speech and Language Therapy
☐	☐	Child and Adolescent Mental Health Service (CAMHS)
☐	☐	Alternative / Complementary Therapies

receiving	needed	**Education**
☐	☐	Learning Support Service (specific reading & writing difficulties)
☐	☐	Speech & Language Support Service
☐	☐	Sensory Needs Service (visual or hearing impairment)
☐	☐	ASD Support Service (autism)
☐	☐	ACE (emotional and behavioural difficulties)
☐	☐	PRESENS (under 5s)
☐	☐	Portage
☐	☐	Transport to school
☐	☐	Transport + escort to school
☐	☐	Use of special educational equipment at school

receiving	needed	**Social Care**
☐	☐	Children's Disability Service Social Worker
☐	☐	Other Social Worker
☐	☐	Residential Short Breaks (Residential Respite Care)
☐	☐	Outreach
☐	☐	Link Plus (Family Link)
☐	☐	Family Support Worker
☐	☐	Community Family Worker
☐	☐	Foster Placement
☐	☐	Adaptations or special equipment
☐	☐	Help/Advice (including financial)
☐	☐	Transport (not to school)
☐	☐	Sensory Loss Team
☐	☐	Direct Payments

Voluntary and Other Organisations

receiving	needed		receiving	needed	
☐	☐	Triangle	☐	☐	Counselling (for parent or carer)
☐	☐	Crossroads	☐	☐	Blue Badge
☐	☐	AMAZE	☐	☐	Childminder

☐ ☐ After school play schemes, such as BHIP, CHERISH, Extratime (please name below):
_____

☐ ☐ Holiday play schemes (please name): _____

☐ ☐ Leisure and sporting clubs, such as Seagulls Specials (please name below):
_____

☐ ☐ National or local support groups (please name):_____

Are there any other services you receive or need?
And, would you like to comment further on any services? (please add a sheet if you prefer):
_____
_____
_____
_____
_____

Ethnic Monitoring

The 1989 Children Act asks that we consider your child's ethnic origin. Please tick one ethnic group:

White: ☐ British
☐ Irish
☐ Traveller of Irish Heritage
☐ Gypsy/Roma
☐ Any other White Background
Asian or ☐ Indian
Asian British: ☐ Pakistani
☐ Bangladeshi
☐ Any other Asian background

Mixed: ☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed Background
Black or ☐ Caribbean
Black British: ☐ African
☐ Any other Black background
Chinese: ☐
Any other: ☐

What is the main language you use at home? _____

Your Name: _____

Thank you for completing this form and registering on The Compass.

If your child has a statement, does AMAZE have your permission to get a copy from the LEA?
It helps us get a better picture of your child's needs.   Yes / No / Not Applicable

Your signature:_____   Date:_____

Signature of child (if appropriate):_____

For looked after children, name of your social worker: _____

Social worker's signature: _____ I confirm that the child's parent(s)
have been informed / given their permission for Compass registration, where legally required.

Please tell us where you heard about The Compass:_____

How easy was it to complete this form? **Easy / OK / Hard**

South Downs Health **NHS**
NHS Trust

amaze

Brighton & Hove

Printed September 2007