

Preventing Social Exclusion of Disabled Children and Their Families

Literature review paper produced for the
National Evaluation of the Children's Fund

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Executive Summary

Introduction

This report presents current evidence concerning the social inclusion of disabled children and their families, and has been developed following an extensive search of academic and policy literature published over the past decade. The focus is on the need for and impacts of preventative (rather than critically responsive) services and strategies for disabled children aged between five and 13 years. 'Disabled children' is a term inclusive of all children who face disabling barriers to social inclusion, irrespective of their impairment. Defining disability and providing estimates of resource needs in relation to impairment is in itself a difficult task. In part because there are differences in definition, there is a lack of accurate and comparable research data on the numbers of disabled children at both national and local levels, which is clearly required to support the planning of appropriate services. The number of children identified as having complex needs has increased in recent years. This can be understood to be the result of a range of factors including improved life expectancy for some severely ill or impaired children, and increased formal diagnosis of and / or prevalence of childhood mental distress, and of Autistic Spectrum Disorders.

Understanding inclusion for disabled children and their families

When examining research literature concerning the experience of disability in childhood it is important to be aware of the different approaches to that experience. A predominant approach has placed impairment related concerns at the centre, which has often led to a focus on biological vulnerability, 'developmental delay', and dependency. This can be implicated in exclusionary discourses e.g. of 'personal tragedy' that can reduce expectations and increase feelings of dependency for parents and children and can reinforce negative attitudes implicated in exclusion. The focus of this review is policy and service responses to socially imposed barriers to participation and inclusion for disabled children and their immediate family members. Ensuring the protection of human rights and access to entitlements for disabled children involves an understanding of the complexity of the individual and family experiences of impairment and disability in social (including socio-economic) context.

Material family resources and implications for inclusion

Barriers to parental economic participation and difficulties faced in housing are core to understanding the problems faced by families that include a disabled child.

Tackling child poverty continues to be central in government initiatives to improve health and welfare outcomes for children. The financial circumstances of disabled children's families has arguably been relatively marginal to policy debate about their social exclusion and inclusion, with financial responses to exclusion subsumed in responses to child poverty which tend to stress parental work as a route to inclusion. There is convincing evidence that families which include a disabled child are more likely to be marginalised economically: this may be for a number of reasons including:

- parental ability to access to work (e.g. availability of appropriate and affordable childcare);
- difficulties when employers fail to recognise parental responsibilities;
- impairment and disability related costs;
- information on, access to, and stability and adequacy of benefits.

Housing and social inclusion

This review focuses specifically on disabled children who live within the family home. The importance of good standards of appropriate housing for households that include a disabled family member is recognised in legislation and practice guidance. It is clearly important not to restrict our concern with the appropriateness of the home as an arena for 'care', and instead understand the home as an important base for family life and personal development (including play and leisure). Housing problems have been linked to negative health implications for family members.

There is a significant body of research which highlights that housing is a priority issue for many low, middle and high income families that include disabled children, with difficulties including:

- Lack of space (for individuals and for the family as a whole)
- Lack of equipment
- Impact of equipment e.g. on space available
- Inadequate bathrooms
- Access difficulties (to and within the home)
- Poor quality housing

Home owners face financial restrictions, particularly as difficulties often include a lack of space and there are significant costs involved in buying a larger home. Social sector renters face difficulties due to a lack of available and suitable properties. Many parents can be unaware of the range of options which might be available, often having not received professional advice or a housing assessment.

Developing integrated services

Research highlights that fragmented services can be disruptive to children and parents, and reduce the overall family time available for leisure and rest. The development of multi-agency working (and, increasingly, integrated services) are key guiding principles in current service development, however barriers exist in terms of systems, perspectives and resistance to joint working (even within agencies). Perspectives on disability and the resulting differences in information held in local organisations may be a barrier here.

Ensuring coordination between agencies and developing multi-agency approaches to respond to children and family needs has been a significant challenge. Families themselves have often had to take on the role of 'coordinators' of services for their children. Current developments (National Service Framework; Every Child Matters and the Children Act 2004; the extension of Direct Payments) are part of the tradition of moving from care away from home to care at home, from specialist towards mainstream provision, and from separate child protection processes to integrated approaches to child welfare which concerned to deliver family support.

Education and social inclusion

Education provision and non-educational services delivered in school settings are increasingly recognised as central to social inclusion. Definitional difficulties in relation to 'disability', 'special educational needs' (SEN) and 'special needs' has led to difficulties in the interpretation of data on the use of services by disabled children. Different understandings within policy development and practice have implications for the organisation and delivery of education based services.

Provision for disabled children and children with SEN has been developed to support inclusion in mainstream schools and has reduced segregation. The case for inclusion and challenges to it need to be understood within the context of a rapid reduction of special school provision and concerns where 'ordinary' schools have been unable to provide a fully inclusive environment. Within any school setting an inter-personal

reiteration of 'difference' by adults to children might be supported by poor resources, and where there is a lack of training and support for teachers in challenging disabling practices.

Children and families often turn first of all to services that they currently engage with and 'Extended Schools' are a potential way of ensuring that non-stigmatising services are offered to disabled and non-disabled children and may strengthen their overall connections with local communities.

Leisure services, play and social inclusion

Engaging in play and leisure activities beyond the immediate home environment can be an important element of participation in local communities. For an individual child leisure and play can help increase psychological well being and physical health, and contribute towards positive social interactions and relationships. Barriers may include topographical aspects of the physical environment, planned and man-made features of streets and parks, the nature of public play equipment, and family resources (including housing difficulties). Attitudes of parents, disabled children, and other adults and children might also be restrictive. Specific resource difficulties (such as lack of funding for services, including availability of trained staff) have been found to affect access to and the provision of inclusive local authority services: this can especially be the case for older disabled children.

Playgrounds are important to support the development of independence and develop social relationships with peers. Responses to the Disability Discrimination Act 1995 and the development of a generally inclusive strategy within England to build up opportunities for play demonstrate that action is being taken here. There is evidence however, that some authorities and organisations might feel paralysed or uncertain about how to proceed when developing play-spaces. Developments beyond work on the design of playgrounds are also identified as valuable: Disability Equality Training could assist youth and play workers to help support the confidence of parents and children and help build relationships at playground sites.

Access to mainstream leisure facilities is an important issue for many families, whose outings may be limited because of lack of funds, lack of transport, lack of disability facilities (e.g. parking, accessible toilets) and concerns about distress (e.g. if queuing is required; if hurtful comments have been experienced or are anticipated). Play

scheme provision can be experienced as an additional resource for the family (and thus reducing stress for parents).

Play services are strongly valued by families who use them, but accessing them is clearly difficult for many families which include a disabled child. A lack of affordable, accessible and inclusive activities can significantly restrict disabled children's involvement with other children throughout the year, and this is often noted during the long school holidays.

'Special' or mainstream opportunities?

There is mixed evidence on whether, how or when special provision for disabled children is able to support young people's development and contribute to inclusion. An important context here is the child's experience of either mainstream or special education and the ways in which education might be networked to other opportunities for leisure. It is also important to consider the ways in which some disabled children's days may be regimented (e.g. by educational and other transport provisions; the location and organisation of medical and other therapies) and geographically fragmented, leaving less space available for play, leisure and family life. Different preferences have been expressed by disabled children themselves, sometimes preferring 'special' provision and sometimes wanting involvement in mainstream activities with siblings. Barriers to inclusion are relevant to both disabled children and their siblings.

Family support

The delivery of specific services to disabled children without addressing other individuals' needs can sometimes marginalise them, and marginalise other family members. Fathers' needs have been highlighted in some research, as supporting parenting has often been equated with supporting mothering (with implications for both mothers and fathers). Work here highlights the importance of whole-family based assessment and access to assessments under the Carers Recognition and Services Act 1995. Research also suggests that the way in which a service is delivered can be inconsistent, e.g. with some families receiving respite services engaging all siblings, and others receiving a service specifically for the disabled child.

Disabled children and their siblings

Disabled children and their non-disabled brothers and sisters will sometimes share needs and wants, and also may have different needs arising from one sibling's

disability (e.g. in relation to leisure and housing related needs for space together and space apart). Difficulties can be individualised by professionals, instead of being understood in social space and inter-personal terms. Non-disabled sibling children can value sibling support groups and 'young carer' organisations. Whilst 'carer' focused approaches in can provide valued services to non-disabled siblings, research suggests that all siblings often primarily consider themselves as brothers or sisters and value prioritising of this aspect of their relationship.

Key messages

- i.** Whilst disabled children and their families may face specific barriers to social participation and inclusion, the needs of disabled children are often the same as the needs of other children.
- ii.** Tackling exclusion of disabled children and their families includes but is not restricted to ensuring inclusion in public spaces.
- iii.** Inclusion needs to be considered with clear reference to children's key relationships.
- iv.** The Disability Discrimination Act 1995 (and subsequent related disability legislation) provides a key context within which to support the development of services
- v.** Education provision for children has clear implications for their social inclusion within the community.
- vi.** Inclusion for this age-group is often explored with reference to education, and this is an important structuring feature of children's lives which needs to be considered alongside other factors within the home and community.
- vii.** Multi-agency working is identified as key by both professionals and parents, and this requires the development of shared understandings.

Chapter 1: Setting the Context for the Review

1.1 Introduction

This report presents current evidence concerning the social inclusion of disabled children and young people, and their families. Within this review, 'disabled children' is a term inclusive of all children who face disabling barriers to social inclusion, irrespective of their impairment (i.e. whether they have a physical or sensory impairment, whether they experience mental or emotional distress, or have learning or cognitive impairments). It is appropriate that this review is not impairment specific: rather it is concerned to identify the range of barriers faced by disabled children and their families which reduce opportunities for social activity and involvement; the review also examines service responses to these. Aspects of disabling and enabling environments experienced by children and families are identified, and the specific focus is on *preventative* measures that aim to reduce exclusion and provide routes to inclusion.

Whilst the primary interest here is disability rather than impairment it is useful to briefly identify some of the disability statistics which indicate the wide relevance of this review. Defining disability and providing estimates of resource needs in relation to impairment is in itself a difficult task. In part this is because the causation of 'exclusion' and related social and individual support needs are understood in different ways, with some (usually clinical) approaches focusing on impairment (or 'pathology') as the source of difficulty, and disability studies approaches instead focusing on disabling environments. It is important to recognise that disability data may be disputed and discussed, yet remain aware that it can have great policy value, and be used to 'galvanize awareness of the relationship between society and disablement' (Fujiura and Rutkowski-Kmitta, 2001, p93).

Even when an epidemiological approach is considered valuable, definitions of 'disabled children' as a group vary, and therefore of course so do population estimates of the prevalence of the experiences of impairment and disability in childhood. There is additionally a lack of accurate research data on the numbers of disabled children at both national and local levels, which is clearly required to support the planning of appropriate services (Ryan, 2004).

There are some indications available about the prevalence of the experience of disability in childhood from official national surveys: for example, the General

Household Survey (ONS, 2004) suggests that about one in 14 children are disabled, whilst the Family Resources Survey (FRS, 2002-2003) has indicated that approximately one in 20 children aged under 16 are disabled (cited by Prime Minister's Strategy Unit (PMSU, 2005). The number of children identified as having complex needs appears to have increased in recent years. This can be understood to be the result of a range of factors including: (i) improved life expectancy for some severely ill or impaired children, and (ii) increased formal diagnosis of and / or prevalence of childhood mental distress, and of Autistic Spectrum Disorders.

The aim of this report is to provide an analysis of disability, childhood, and social inclusion, and it does not seek to provide an impairment specific review. It is important that disabled children should not be considered to be a homogenous group given that there is great variation in childhood experiences, including impairment type and family socio-demographic characteristics. Some disabled children may encounter a small number of barriers which they and their families can challenge and overcome, whilst many other disabled children in Britain can be identified to be at high risk of social exclusion. Family poverty may be more likely, and this is particularly the case where more than one family member is a disabled person, if there are significant care (or child care) costs, and/or parents are unable to work in paid employment. Disabled children can additionally face further physical, attitudinal, and policy and practice based barriers to full social participation, which may impact on their long-term aspirations and opportunities. Disabled children and their families also largely share a particular welfare context as they may also be able to access disability focused supports (e.g. via education, health, social security, or social services) which may have positive and negative impacts on children's and families' lives. Despite, then, the importance of awareness of heterogeneity, it is possible to review evidence concerning social inclusion for this group of children and families as a whole.

1.2 Reviewing the Research

The central purpose of this review has been to examine the currently available research evidence concerning the need for and impacts of preventative (rather than critically responsive) services on disabled children and their families. The primary focus has been on the evidence concerning children aged between five and 13 years, reflecting the Children's Fund's focus on reducing the risks to and impacts of social exclusion amongst this age group. This provides a different focus from the PMSU (2005) research and policy review which focused predominantly on the needs

of families with younger disabled children, aged under-five, and older disabled young people facing transitions to adulthood.

Discussion of inclusion and disabled children of school age is often restricted to exploring education and the school inclusion agenda. Within this review there is not the space to do justice to the extensive evidence available here, and by having a primary focus on the child's experience of family alongside non-educational community services I have attempted to redress the balance. For example, I have tried to ensure a focus on understanding children and families' experiences with close reference to social contexts and have not followed a developmental or individualising approach. It has remained important to acknowledge that education-based provision is central for services developed for disabled children, and so this has also been included to identify some key messages from research.

Given the broader interest of the Children's Fund in preventing exclusion for all young children, a consideration of the impact of services on children and their families requires that non-disabled siblings' experiences and needs has also been a consideration within this review.

Identifying materials

A wide range of databases / sources have been accessed to identify relevant materials which have been published since January 1995:

- Department of Health, Department for Education and Skills and the Office of the Deputy Prime Minister's websites were searched, and each have provided valuable material and further references.
- Web of Knowledge, ASSIA, and Social Services Abstracts databases have been searched electronically.
- Research in Practice and the Electronic Library of Social Care have both provided valuable sources of practice focused materials, and the Joseph Rowntree Foundation has been a useful source of research reports and summaries.
- Books have been identified via the above processes, and also through searching the British Library Catalogue.

- Finally, voluntary organisations websites have been searched (e.g. Contact a Family; Barnardo's; Family Fund Trust) which has uncovered extremely invaluable research materials.

Where electronic searches could be undertaken key search terms were used in combination with one another: "Prevent*" (prevention, preventing); "Disab*" (disabled, disability); "Child*" (childhood, children); "Disabled child*"; "Child* with disabilit*"; "Policy" and "Policies"; "Service" and "Services". In addition, given the different terminology within education, "Special needs" and "Special educational needs" were also used within the searches conducted.

Given the range of search terms that have been required, and the broad approach taken to inclusion and disability, the screening of the material has been a significantly lengthy process to ensure that a focused review can be provided. Over 1000 references were downloaded into an EndNote file. I then searched to exclude any irrelevant items, and the remaining selection then functioned as a library which I could search for the most relevant materials. It is important to state that within this relatively brief period it has been possible to provide a clear 'map of the ground' in terms of the research evidence, and to ensure that central messages from research are identified. There is a broader research literature (i.e. including much more clinically, psychologically or educationally based) which it has not been possible to fully integrate within this already-broad review.

1.3 Approaches to Understanding Disabled Children and Their Families

Priestley (1998) has identified a number of approaches in childhood disability research which produce different types of understanding of what is central to the experience of young disabled people and their families. A predominant approach to disability has been that which places impairment related concerns at the centre. Historically, and particularly in relation to children, this has constructed the issues in terms of biological vulnerability and 'developmental delay'. The disabled child therefore becomes primarily understood as exceptionally dependent (rather than active and social). Priestley further highlights how, in recent times, the funding of (and publication from) both 'social' and medical research has largely been that which has seen impairment as central, and so often results in research that 'sees' impairment first, and childhood and family experience as peripheral. There are particular academic and public discourses that can feed from and into impairment focused work (such as impairment as 'personal tragedy') which themselves can be

exclusionary and oppressive. For example, as Middleton has highlighted, traditional explanations of the disadvantages and exclusion experienced by disabled children have considered the 'trauma of impairment' to itself be an explanation (Middleton, 1999).

In order to maintain a broader and deeper perspective on childhood and family experience it is vital to identify the most relevant non-clinical research agendas in this area. Both disability studies and broader rights-based approaches to studying childhood are critical of medicalising approaches to research and therefore present alternatives: from a disability studies perspective, **structural and inter-personal barriers to participation** are identified as being of central importance; from childhood studies a consideration of 'children first' (rather than defining people as of little concern beyond their impairment) places **children's rights** firmly at the centre of this research agenda.

Within this review these contemporary research agendas are at the centre, alongside recognition that medical and psychological elements are valuable within holistic accounts of disability (Dewsbury, Clarke, Randall, Rouncefield and Sommerville, 2004). For example, where impairment specific approaches are included within this report, it is where there is an important contribution to understanding children's and families' perspectives, experiences, constraints and opportunities in both private and public arenas.

There will not be space here to explore fully the range of research agendas that have relevance to exclusionary processes and preventative approaches to disability and childhood. For example, whilst not the remit of this review, it is important to note that understanding the experience of disability can also usefully be considered from a development in social context perspective. This has been explored elsewhere: for example, Bricourt, Porterfield, Tracey and Howard (2004) have attempted to develop an ecological systems approach to children with reference to models for understanding 'children with developmental disabilities'.

Disability studies and the social model

The clear starting point for an analysis of the evidence is recognition of the importance of the social model of disability in analyses of barriers to inclusion for disabled people. The distinction between impairment and disability is a valuable contribution of the Disability Movement in Britain (UPIAS, 1976), which has

developed in its range of application and use over the past thirty years. It enables a clear focus on social barriers that can result in exclusion from full social participation, i.e. the social, environmental and inter-personal barriers that disable individuals (and their families) in preference to a narrow focus on the impact of impairment. It has been imperative to campaigns which have contributed to the development of anti-discrimination legislation, particularly the Disability Discrimination Act 1995 and the Special Educational Needs and Disability Act 2001. Whilst the social model continues to be a source of theoretical debate within disability studies (for example, in relation to how to capture the experience of impairment), it clearly exerts a significant influence on disability and social policy academic research, and official policy agendas. This approach to analysing disability can now be seen to have provided a 'barriers' focus in the UK Government strategy on combating disability and improving disabled people's life chances, from early childhood and through the life course (PMSU, 2005).

Social model approaches have been developed and applied to understand the experience of disabled people in relation to personal autonomy, including access to public space and public roles. There is clear value in examining barriers faced in both the private and public realms, including developing a specific focus on the experiences of disabled people (including children) within the context of specific private (e.g. family) roles and relationships. A family-level application, demonstrating the relevance of the social model to understanding child and family experience, is provided by Dowling and Dolan (2001). They have drawn from the qualitative data developed in their research, using a social model approach to identify the inequalities experienced by disabled children and their families. They develop an argument that whilst the social model is usually drawn upon to enable understanding the experience of (groups of) individual people with impairments, in the case of disabled children it is especially necessary to include the family experience of disabling barriers, as individuals' opportunities and experiences are so bound up with one another in their familial relationships. Their analysis highlights the family implications of socio-economic inequalities as well as the impact of macro-level organisation of social care on outcomes for the disabled child *and* for other family members. When approaching social exclusion from this perspective, addressing poverty and housing quality are likely to be vitally important to many children's experiences (for example in relation to enabling participation in local communities, and developing relationships with adults and children beyond the immediate family and beyond specialist service provision).

Social model critiques of medicalising approaches also contribute to understanding disability in the context of family relationships when they identify the potential impacts of the 'tragedy discourse' on parents' thoughts, feelings and aspirations for their children, and subsequently on children's development. Avery (1999) considers that the ways in which parents are informed of their child's impairments often can be an induction into a limiting approach to their child, reducing aspirations and increasing dependence, both of the child and parent, to medical and psychological interventions. Further consideration of inter-personal experiences between parent and child, and family members and professionals can add greater depth to research findings that focus on structural barriers or individual experience (e.g. see Brett, 2002). In particular, in social model terms, for disabled children who encounter low aspirations of professionals and parents, this experience can be considered to be an inter-personal barrier to personal autonomy and social inclusion *potentially over the life course*. Challenging negative attitudes and low expectations is an important element of ensuring social inclusion. These inter-personal aspects of disabled children's socialisation have been considered in relation to disabled professionals' success in adult life (Shah, Arnold and Travers, 2004), and point to the need for preventative work to identify the life course implications of countering disabling barriers. Interestingly, the government is beginning to develop a 'life course' based strategy to ensuring opportunities and choice for disabled people (PMSU, 2005).

Disability, children and human rights

... if we start out by assuming that disabled children and their families should have access to experiences which others routinely expect, the issue then becomes one of finding the route to achieve it and the services that will enable it to happen.

(Read and Clements, 2001, p15)

Over the last twenty years, the Disabled People's Movement in Britain has ensured the development of focused attempts to understand and challenge the oppression and discrimination faced by disabled adults and children. During the same period there has been an extensive widening of national and international recognition of human rights which can become part of claims for justice through social care and welfare provision. Clements and Read (2003) explore this in their review of the implications of the 1998 Human Rights Act for disabled adults and children, with reference to health care and the right to life, to the right to private and family life, the right to education, and the right to expression and to be heard. The language of

human rights has become a key part of the expression of the social model of disability in political and legislative terms.

In relation to children, it is useful to consider the expression of rights in the UN Convention on the Rights of the Child (1989), which was ratified by the UK government in 1991 and the Human Rights Act 1998. This applies to all children and young people aged under-18 and provides a strong framework under which to promote social inclusion. Compliance is required in international law and therefore regularly monitored by the Committee on the Rights of the Child (Badham, 2004). Morris (1998) identifies these rights with direct reference to disabled children as follows:

- Disabled children have the human right to be included in their local community and to do the kinds of things that non-disabled children do. They have the right to support to help them do this.
- Disabled children have the human right to take part in play and leisure activities and to freely express themselves in cultural and artistic ways. They have the right to equal access to cultural, artistic, recreational and leisure activities.
- Disabled children have the human right to live with their parents unless this is not in their best interests. They have the right to services to make it possible for their families to look after them.
- Disabled children have the human right to express their views and for these to be taken into account. They also have the right to freedom of expression.
- Disabled children who spend time away from home because they need care or treatment have the human right to a review of the placement at regular intervals.
- Disabled children who do not live with their families, temporarily or permanently, have the human right to special protection and assistance which takes account of their ethnic, religious, cultural and linguistic background.
- Disabled children have the human right to be protected from all forms of abuse and neglect.
- Disabled children have the human right to privacy.

(Morris, 1998, pp9-10)

The identification of barriers can arguably be stated in a very holistic way when this is with reference to such a broad range of rights and entitlements to access social support and social opportunities, rights to receive protection from harm, and rights to individual expression and privacy. For example, the right to expression and to be heard is evidenced in work which actively involves young people in decisions about their lives, and is particularly valuably articulated by Morris in her guidance for those working with young people with communication impairments (Morris, 2002).

Realisation of rights and entitlements, including access to appropriate and enabling support, can be restricted if a medicalising approach is adopted. For example, Morris (1998) identified ways in which the framing of the Children Act 1989 either could either support or limit disabled children's access to their rights under the UN Convention. Morris argues that a crucial difficulty is the way in which the language of and implementation of the Act was often based on a medical model approach which could lead to restrictive assessments and allocations of resources, and that a social model interpretation is required to positively enact rights when implementing legislation.

The UN Declaration of Human Rights is clearly an important element of a strengthened understanding that disabled children's needs are essentially the same as other children's needs, as has been identified in recent service standards:

Disabled children and young people are first and foremost children, with all the rights, needs and aspirations of all children and young people. Ensuring their rights are met requires providing services for them that are in line with the *United Nations Convention on the Rights of the Child; the Human Rights Act 1998 and the Disability Discrimination Act 1995*.

(Department of Health, 2004, p7)

Both human rights and disability discrimination legislation have created legal obligations for service providers, and in reviews of current practice the (at least potential) routes to inclusion via human rights claims is clearly expressed. Beresford and Oldman (2000) identify the relevance of the United Nations Convention on the Rights of the Child when considering the implications of poor housing for disabled children. Clements and Read (2003) identify that the European Court of Human Rights has considered complaints from parents seeking mainstream education for their disabled child, and those seeking a particular 'special' school education; it currently seems that domestic legislation provides a stronger entitlement to mainstream education. The Audit Commission (2003) conducted research with young people from Triangle, an organisation working with disabled children. They identify from their work that the UN Convention on the Rights of the Child is central to delivering to disabled children and that 'if the child's rights are not delivered, the whole family is disadvantaged' (p11). The impacts of disadvantages through relationships are reiterated by Mencap (2001) who conducted research with parents of disabled children, and linked the denial of human rights to (both young and adult) children to also be a denial also of parental human rights.

1.4 Conclusion

The experience of childhood disability raises research questions of direct relevance to researchers and to policy makers across health, social care, housing, welfare, education and disability agendas. There are also a diverse range of perspectives that attempt to develop understanding of the experience of disabled children and their families.

This review has taken an inclusive and social approach in its definition of disability, and therefore the experience of disabling barriers and how this can be challenged and removed is the unifying concern. The experience of disability can be explored from both an individual 'functioning' (including individual social participation) perspective, and by looking at the whole family experience. It is valuable to understand the inter-personal experience of disability with reference to possible consequences for childhood experience and personal development, rather than perceiving barriers as 'static' environmental features. There is therefore a particular focus on children's participation in their families and within their local communities. Of key concern is the support families require to ensure that disabled children *and* their siblings and parents can have and maintain a quality of family life without vulnerability to social exclusion. This is where the in-depth review begins, with a focus on the material resource issues facing many families that include a disabled child.

Chapter 2: Material Family Resources and Implications for Inclusion

2.1 Introduction

The Children's Fund has at its centre a concern with multi-agency approaches to early intervention to reduce social exclusion and improve outcomes for young people and their families. As the Audit Commission (2003) have highlighted, barriers to parental economic participation and difficulties faced in housing are core to understanding the problems faced by families that include a disabled child. It is clear that whilst socio-economic disadvantage is not the only cause of social exclusion, the poverty faced by some families cannot by any means be 'left to one side' in this review.

Tackling child poverty continues to be central in government initiatives to improve health and welfare outcomes for children (for instance, as stated in the National Service Framework for Children, Young People and Maternity Services, DoH, 2004). It is within this policy context that this report reviews research which provides insight into the extent to which the family resources, including the home, support or restrict opportunities for inclusion.

2.2 The Financial Circumstances of Disabled Children and Their Families

The financial circumstances of disabled children's families has arguably been relatively marginal to policy debate about their social exclusion and inclusion, with financial responses to exclusion subsumed in responses to child poverty which tend to stress parental work as a route to inclusion. Family poverty is an important place to start this review, despite (or because), as Preston (2005) highlights, current Governmental focus for these families has been much more concerned with tacking poor service systems/provision than addressing unmet financial needs and short-term financial insecurity.

Economic exclusion and disability

The finances required for social participation may be increased by disability of a family member, with average costs of raising a disabled child estimated to be around threefold, (Dobson and Middleton, 1998). The family finances available will also be reduced if adults are unable to work, or have reduced incomes as a result of parenting a disabled child, particularly if the support for that child is under-resourced from outside the family. And whilst disability may result in additional costs, the

benefits available to families are not always accessed, nor do they always meet the real costs (Sharma, 2002a).

There is convincing evidence that families which include a disabled child are more likely to be marginalised economically. This is recognised within some strategies that respond to child poverty (e.g. in relation to childcare, identified below): Sharma (2002a) has called for a specific economic analysis to be undertaken to identify the required investment to ensure disabled children are lifted out of poverty by the Government's policies in this area.

Gordon, Parker, Loughton and Heslop (2000), in their reanalysis of the OCPS Disability Surveys (1986), considered that a majority of families which included a disabled child were living in or on the margins of poverty. Whilst this finding does not allow us to specify current experience of poverty in this group, the authors briefly allude to an interrelationship between poverty and disability:

It is clear that there are sharp differences in the prevalence of childhood disability according to the social class of the household or family. 'Working-class' children have a higher risk of suffering from a disability than children from the 'middle' and 'upper' classes.

(Gordon *et al.*, 2000, p247)

Gordon *et al.* (2000) identified that children were three times as likely to be disabled if their father was an unskilled manual worker as compared to children of fathers who were professional workers. Whilst this relationship is based on relatively old data, it should not be disregarded as it does raise a number of key questions concerning the extent to which poverty and economic hardship might be correlated with impairment and present barriers when parents and young people attempt to negotiate their access to and use of services. This is all of interest given that concerns have been raised within the research literature about assumptions, usually implicit, that families of disabled children (or at least those in contact with services) are more likely to be middle class. Such assumptions may be because of the comparison that is sometimes drawn with families that are in contact with child protection provision (e.g. see Axford and Little, 2004: quoted on pp23-24 within this review). In addition, in parallel with the emergence of the disability movement, it is likely that the most vocal voices of and for families that include disabled children are those (usually middle class) parents with the resources to engage with policy making and the development of service provision. Within research looking at the experience of black and minority ethnic families a middle class and culturally white framing of needs has been

identified in many organisations, which can exclude and marginalise service users (Broomfield, 2004).

Recent population survey research by Emerson and Hatton (2005) identifies the range of socioeconomic circumstances of children and families, with estimates for the population of different forms of disadvantage. They analysed the 2002 data from the Department of Work and Pensions *Families and Children* study which surveyed over 7,000 families that included a dependent child below the age of 17. They identified households where parents reported a child to have long-standing illness or disability, and/or special educational needs due to physical impairment, and/or 'intellectual disability' that impacted on their schooling. From this they identified that approximately just over **one million** families included a child 'at risk of disability', and that such families were 1.45 times more likely than other families to live in poverty (37 per cent versus 29 per cent of families). Some further key estimates from their analysis included that:

- 475,000 families supporting a child at risk of disability were in debt; and
- Over 350,000 families supporting a child at risk of disability were worried about money 'all the time' or 'quite often'.

These estimates would suggest that for around a third of families including a disabled child, anxiety about finances (as well as the material stressors of poverty) would increase stress and reduce choice and opportunity.

Gordon *et al.* (2000) found that parents of disabled children were much less likely to be in full time work than other parents. Emerson and Hatton (2005) found that households including a child at risk of disability were over twice as likely to be workless. Those parents who do work are more likely to be on low incomes (Reith, 2001). A number of factors may reduce disabled children's parents' opportunities for employment. Research programme findings from a number of projects funded by the Joseph Rowntree Foundation highlight how combining caring for a disabled child and any paid employment is likely to be extremely difficult wherever employers fail to recognise parents' caring responsibilities, and that children's services (including health and education) make assumptions that disabled children's parents do not work (Joseph Rowntree Foundation, November 1999). Access to affordable and appropriate childcare is crucial to all parents, and is currently stressed within the Government's 'Ten Year Strategy' for childcare (HM Treasury, 2004) which recognises that families with disabled children may find it difficult and / or expensive

to access such services. The strategy also highlights the need to extend the 'right to request' (though clearly not to guarantee any level of) flexible working to parents of all children.

Support in relation to the costs of disability may be crucial to family welfare: access to, and holding on to, disability benefits may be one way in which families can at least in part restore income levels and so combat exclusion. Preston (2005) has conducted valuable qualitative work to evaluate the impact of disability benefits within 20 families which include a disabled child. This work has identified that Disability Living Allowance is particularly valued in improving the well-being of the child, and therefore of the whole family, but the study did highlight the stress caused to families by (anticipating or encountering) fluctuations in income if DLA is reduced or removed. There are barriers involved here that require specific recognition within this review. One element is the psychological experience of being assessed for benefit: applying for disability benefits may be emotionally trying for parents given that it can demand a focus on negative aspects of the child's current experience (as recognised by Watson, Lewis, Townsley, Abbott and Cowen (2004) in their advice to parents). In addition, there is a need for clearly produced, accessible and appropriate information which actively supports access to benefits for those who are eligible. For example, differential receipt of disability benefits by families from black and minority ethnic (BME) communities has been identified by Chamba, Ahmed, Hirst, Lawton and Beresford (1999), who compared income and benefit receipt among white and black and minority ethnic families caring for a disabled child within two separate research studies. Of relevance here, though of course but one factor, is the importance of producing information on benefits in the range of community languages (Sharma, 2002a). Additionally Chamba *et al.* (1999) identified that even where disability living allowance was paid to minority ethnic families caring for a 'severely disabled' child this was less often made at the higher rates. And whilst many families might find that information about benefits is sparse, where a child has a 'hidden disability' parents may be likely to receive little if any information about disability benefits, and struggle to hold onto any benefits received. For example, Cavet (2000) reports the experience of a mother in this situation:

... one mother who had accepted the withdrawal of Disability Living Allowance for her son, despite his use of twice-daily rectal washouts and much spoilt clothing and extra laundry said: 'Sometimes you get so tired of fighting, trying to, you know, get your point across or whatever ... sounds like you're constantly *begging* all the time ... you know, so you just don't, you just don't bother' (mother of David, 16 years). (Cavet, 2000, p625)

Specific issues that parents have identified as requiring redress by government have been reported by Preston (2005), vis-à-vis ensuring that DLA and other disability benefits have a role in eradicating poverty where it exists due to a child's disability. Maximising take-up through development of advice centres, publicising benefits (e.g. via schools), and ensuring hidden or fluctuating conditions are responded to in assessment were key issues raised here. Access to disability benefits is of relevance to the full range of services with which families come into contact. For example, Steyn, Schneider and McArdle (2002) highlight this within their research of the use of DLA for children with Attention-Deficit/Hyperactivity-Disorder. They found that general practitioners and health care professionals (often involved in assessing impairment for benefit purposes) received insufficient training in benefits and in their potential role of signposting to benefit and welfare advice services. The research therefore highlights that shared professional knowledge of support available could improve the socio-economic circumstances of families, and in particular that educational and care workers within schools and doctors surgeries/health settings could all be a useful resource.

2.3 Housing: Core to Social Inclusion

This review focuses specifically on disabled children who live within the family home. The importance of good standards of appropriate housing for quality of life in households which include a disabled family member is recognised within the Carers and Disabled Children Act 2000 (DoH, 2001a), and developed within the practice guidance concerning disabled children (DoH, 2001b).

We should not restrict our concern with the appropriateness of the home as an arena for 'care': Allen (1999) alerts us to the dangers of assuming that policies which regulate 'special needs' within the home necessarily produce a significant move forward from those which were unquestioning about the exclusionary practices of long-stay institutional care. This needs to be explored as strategies towards inclusion which are not directly linked to life within the home may nevertheless be compromised by difficulties faced in relation to the home environment.

Housing and rights-based approaches to inclusion

For disabled children and their families, living in an unsuitable home can affect parents' mental and physical health and their needs for specialist support services. For the children, the impact is widespread, with a lack of spontaneity and variety in their home lives, and no, or limited opportunities to develop independence and self care skills.

(Beresford and Oldman, 2002, p1)

Research conducted by Beresford and Oldman (1998, 2000, and 2002) has been invaluable in raising awareness of the day to day implications of housing difficulties for families which include a disabled child. For example, Beresford and Oldman (2000) have presented access to suitable housing as central to basic human rights and yet have identified a low level of awareness amongst key professionals of its importance. This professional lack of awareness reflects the way in which disabled children's needs are most usually assessed under the Children Act 1989, in which housing is hardly addressed beyond brief reference to adaptations within its guidance. In contrast, the Framework for the Assessment of Children in Need and their Families (DoH, 2000) identifies family and environmental factors (including housing), as key to understanding a child and his or her developmental needs. The specific rights identified by Beresford and Oldman (2000) as highly relevant to housing needs are the rights of children:

- to be included in their local community and to do the things that non-disabled children do;
- to take part in play and leisure activities and to freely express themselves in cultural and artistic ways;
- to live with their parents unless this is not in their best interests;
- to express their views and have these taken into account.

The concern to ensure children do express their views and that this is meaningful participation is increasingly reflected in research and practice. This remains a salient issue in the delivery of housing (and other) services: for example, the Audit Commission (2003) cite a housing officer on whether children's voices are heard:

Users need greater awareness of what's on offer so that they can identify their choices. But there's the issue of the needs of the parents versus the needs of the child. Young people face barriers to achieving greater levels of independence, including with housing because of perhaps over-protective parents.

(Audit Commission, 2003, p21)

Housing needs

Families which include a disabled child are more likely to be tenants than owner occupiers, and both these groups will be faced with different legislation if looking to public support in improving their housing. There is now a significant body of research which highlights that housing is repeatedly one of the priority issues for families which include disabled children. For example, Sharma (2002a) reports from research for Barnardo's (also Sharma, 2002b) that 14 out of 17 families interviewed had significant housing needs. Bywaters *et al.* (2003) found within their sample of 15 Pakistani and five Bangladeshi families in contact with an advocacy service, that improving housing was most often the main priority.

Large scale survey research also reiterates this as a key issue. Emerson and Hatton (2005) estimate from their study that 85,000 families in Britain supporting a child 'at risk of disability' are living in overcrowded accommodation, and that 52,000 families would consider their homes to be in poor repair. From their survey involving over 2,500 parents and over 100 practitioners, Beresford and Oldman (2002) identify a range of ways in which disabled children's families experience problems with inadequate housing. The majority (around 90 per cent) of families experienced at least one difficulty, with problems including lack of space, location, inadequate bathrooms, poor housing, unsafe internal environments, access problems and the lack of equipment. Whilst the number of difficulties faced was associated with income and tenure, even amongst the higher/middle income families who cited fewer difficulties an average of three housing problems were reported. Whilst many families may face some housing issues, amongst the population of families which include a disabled child it is likely that families from minority ethnic communities are even more likely to experience unsuitable housing (Chamba *et al.*, 1999).

Beresford and Oldman (2002) found that where families wanted change to their current housing situation, their preference was usually to move home rather than to make adaptations. Home owners faced financial restrictions, particularly as difficulties often included a lack of space and there are significant costs involved in buying a larger home. Social sector renters faced difficulties due to a lack of available and suitable properties. Many parents were unaware of the range of options which might be available, having not received professional advice or a housing assessment. In addition, Beresford (2002) has found significant amounts of unmet equipment needs in relation to lifting and other mobility support, safety, communication, bathing, toileting, learning and playing. Such equipment can improve

the child's and family's experience at home, but a significant further need identified concerned childcare support from others (e.g. relatives) in different home environments, and a need for equipment.

Some of the implications of housing problems for health and well being have been examined by Oldman and Beresford (2000), reporting from interviews with disabled children and their families. They found that health emerged as an unprompted but central theme in their research on housing, and argue that the relative neglect of health and housing issues in disability research reflects the Disability Movement's concern to counter the medicalisation of disability. By way of context to their own findings, they highlight that the family home cannot always be viewed as benign. For example, restrictions to accessing different areas might be used to keep disabled children 'in their place'. This expands on the point made above from research by the Audit Commission, and together the evidence highlights concerns about disabling environments and assumptions that home and community settings tend towards supporting inclusion. There are clearly shared issues of concern within families with implications for the health of all family members. For parents and children in Oldman and Beresford's (2000) study, both limited space and limited access to some areas of the house were identified, and these reduced opportunities which would support family physical and mental health (e.g. to exercise, to undergo therapies, to interact, to have personal space and privacy). Unsurprisingly, a lack of suitable adaptations which led to significant amounts of lifting also had health implications for parents.

Social model, impairment, and housing needs

There is not space within this review to examine different experiences of impairment and family life in-depth a propos housing needs, although it is important to recognise that some specific housing needs are likely to exist in connection to specific impairments. For example, research which focuses on children who are technology dependent highlights that some impairments will lead to very specific home environments. Kirk and Glendinning (2004) have looked at the experiences of parents who care for a technology dependent child at home, and found that parents identified the way in which the presence of equipment, of nursing/support staff and other professionals resulted in a medicalised home environment. Whilst many families with disabled children (whatever their impairment) may face difficulties regarding play space, it would seem that medicalised homes may lead to a particular set of stresses for all family members if there is a lack of other spaces and a lack of opportunities to have family time in other environments. For children who have a

sensory impairment, again, specific issues may be more pertinent. For example, Allen, Milner and Price (2002) highlight from their interviews with 44 visually impaired children and their parents that home environments were most often considered unproblematic, but the immediate external environment was viewed as causing difficulties relating to children's play needs and safety.

In relation to service responses, not only does it seem that housing is insufficiently addressed where disabled children are identified within families, but also that disability itself is quite narrowly defined when housing has been recognised as an issue (i.e. with a focus on physical impairment). Beresford and Oldman (2002) develop this point, by calling for an incorporation of social model thinking more fully into conceptions of housing need in order to understand the range of housing needs amongst disabled children as a group overall, to ensure more appropriate responses to individual disabled children and their families:

Central to any reconceptualisation of housing need has to be a broadening of the 'accepted' definition of disability. At the moment the very different housing needs of children with learning difficulties, those with socio-emotional and behavioural problems, and those with significant healthcare and nursing needs, are not acknowledged within policy, or by service providers. The focus is very much on physical disability and the issue of access. Yet we know that among the population of severely disabled children, most will have more than one type of impairment or disability.

(Beresford and Oldman, 2002, p36)

Beresford and Oldman (2002) did find some evidence that, where they did take place, some housing assessments were inclusive of factors such as the need for family space for all family members, and the need for play space.

Whilst a number of difficulties have been identified in relation to housing, it is clear that well-designed housing adaptations can improve quality of life (Audit Commission, 2003), including health (Heywood, 2004). Practical guidance has also been developed by the Joseph Rowntree Foundation, which can usefully support practice in this area (Bevan, 2002). Improvements in delivery of housing services (including equipment and adaptations) are likely to be delivered through the specific relevant standards included in the National Service Framework for Children.

2.4 Conclusion

Whilst poverty and exclusion are not entirely synonymous (i.e. well-off disabled children and their families may experience exclusion due to disability) it is clear that

the socio-economic circumstances (including housing) of families are a context for understanding exclusion. Disability, income, housing and health issues often interact, and many families that include a disabled child are likely to face some similar difficulties to other families living in inadequate or poor environments.

The psychological and material impacts of poor housing and income will reduce all family members' resources for increasing activity within the home, and engaging in desired activities outside the home. The research reviewed above indicates that strategies for inclusion cannot be limited to activities in public spaces (at its most broadly defined), if the housing and financial difficulties faced more privately by families on a daily basis are not addressed. This is a valuable context in which to place the remainder of the review, which is focused more specifically on service provision.

Chapter 3: Current Directions in Service Provision for Disabled Children and Their Families

3.1 Introduction

In introducing this review, it was highlighted that human rights and disability rights approaches provide a key context within which to consider service delivery to disabled children and their families. Together they provide a useful framework from which to consider recent legislation and associated developments in the provision of services. For example, the Disability Discrimination Act 1995 highlights the importance of access to services, both 'mainstream' and specialist. The Audit Commission (2003) reiterates that the Disability Discrimination Act 1995 (and the subsequent Special Educational Needs and Disability Act 2001) has been an important driver in the improvement of services for disabled children and their families. The Council for Disabled Children (1999) have, however, reported in their review of local authority responses to Quality Protects (DoH, 1999) that significant work was required to ensure that the intended impact of the Disability Discrimination Act 1995 occurs. For example, strategic planners were found to have little awareness of the implications of the Disability Discrimination Act 1995 for delivery of services, with a further lack of local data on population needs impeding a strong response to the requirements of the Act. The creation of the Disability Rights Commission in 2002 has increased the strength of the challenge to services to respond proactively to the rights and needs of both disabled children and adults (Russell, 2003).

3.2 Current Directions: Developing Integrated Services

Ensuring coordination between agencies, and developing multi-agency approaches, is a significant challenge. For example, some difficulties were identified in an SSI inspection programme of services to disabled children and their families conducted in 1997. This focused on eight Social Services Departments, and in each case explored inter-agency approaches with the voluntary sector, health and education. Two resulting reports (*Removing Barriers for Disabled Children* and *Disabled Children: Directions for their Future Care*) presented the evidence from the inspections and the outcomes of parallel initiatives and research. In bringing these reports to the attention of Directors of Social Services, the Chief Social Services Inspector raised a number of concerns about the ways in which services were offered to children and their families (Social Services Inspectorate, 1998). These included:

- A range of barriers to (and a limited range of) services.

- The rarity of needs-led assessment in Social Services Departments.
- A lack of staff training and a lack of staff groups with appropriate skills and knowledge.
- A lack of transparency to services users in terms of the roles and responsibilities of the different professionals who were working with them.
- Limited progress in joint planning and joint commissioning.

The move towards family support is important to stress within this review, given the acknowledgement that childhood disability can have implications for the whole family and family experiences can impact on individual children's opportunities and development. Walker (2002a) has identified that family support has received significantly less focus than immediate statutory protection concerns in British policy despite both being core within the Children Act 1989. In addition, family support was the underpinning within the 1989 UN Convention on the Rights of the Child. Legal provision has developed over the last fifteen years to provide a basis for family support (e.g. see Walker, 2002b), and therefore more preventative services. Gardner (2003) also identifies family support as a key element in current government policy (in relation to poverty, education, and access to services) and that it 'is increasingly seen as one means to an overarching social policy goal, the promotion of social competencies and prevention of social exclusion' (p2). She identifies family support based interventions as promoting family assets (rather than identifying 'deficits' – a common critique of medical approaches to disability and family life).

More holistic responses require greater cross-agency cooperation and multi-agency approaches. Families themselves have often had to take on the role of 'co-ordinators' of services for their children, which can be a source of stress for parents (Limbrick-Spencer, 2000; Watson *et al.*, 2002). This is perhaps particularly the case when parents take on this role but feel that their particular expertise and knowledge is not appreciated and taken on board by professionals (Britton, 2001).

Across agency working can be seen to be on a continuum. It can include offering key worker support to parents; support for families and assistance with gaining information and coordinating input; the provision of a formal 'service coordinator' (as discussed by Beattie, 2000), through to joint provision of services, and fully-integrated multi- or inter-disciplinary services. Whilst there is clearly room for a variety of models to be followed in different localities, an integrated approach to

providing children's (health, education and social care) services is central to the National Service Framework (NSF), (DoH, 2004), and the 'Every Child Matters' Green Paper (DfES, 2003) which is continuing to inform legislation (particularly the Children Act 2004 which implemented the main proposals). Axford and Little (2004) summarise how these current developments are part of the tradition of moving from care away from home to care at home, from specialist towards mainstream provision, and from separate child protection processes to integrated approaches to child welfare which concerned to deliver family support. They also identify very specific elements within current documents, including the importance given to service user involvement in service design, to needs-led practice, and to evidence based practice.

The National Service Framework

The National Service Framework (NSF) for Children (DoH, 2004) has been set up as a ten year programme which aims to develop services that are child and family-led rather than organisationally driven. It is valuable to flag up the NSF Disabled Children's Standard (Standard 8), which is the central principle around which local service standards that are specific to disabled children are to be developed:

Children and young people who are disabled or who have complex health needs receive coordinated, high-quality child and family centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.

The main intended outcomes of this standard are presented as including improving health care and social care interventions, including diagnosis, assessment and access to services; and developing better early intervention and multi-agency responses, including the use of key workers and direct payments.

Every Child Matters

Every Child Matters (DfES, 2003) is a central element of the Government's strategy to tackle social exclusion among families with children (see ODPM, 2004a). This Green Paper for England was built both on concerns about past child protection failings, and an aim of integrating child protection and specialist services for children in need within the context of universal services. Axford and Little (2004) sum up the policy development contribution of 'Every Child Matters' in the following way:

As well as giving greater stress to practical supports (than to process), integrated or 'joined up' services (than to isolated interventions), needs led provision (than to service-led solutions) and to being proactive (moving away from endlessly reacting to problems as they arise), future children's services

are to work to the same standards regardless of whom they are provided for. It will no longer be satisfactory to have one set of provision for poor children (e.g. most child protection cases) and another for children in need those whose parents are more articulate and middle class (e.g. many of those with disabilities). These common goals are improved quality of life for children, reductions in impairment and minimising social exclusion.

(Axford and Little, 2004, p17)

There is not space here to review the extent to which past divisions in children's services mirrored a socio-economic split in terms of the service users worked with. There are however clearly broader issues of social inclusion which shared standards within services can support by reducing the stigmatisation and marginalisation of the most vulnerable families.

A common assessment framework has been identified as central to the implementation of Every Child Matters, to ensure that assessments build on previously collected information, reducing the possibility that parents and children would need to 'tell their stories' again and again. Also key is supporting parents and carers through both universal services and targeted specialist services. Integrated services and information availability are themes throughout, with the development of key worker provision an important method identified here.

In addition, the potential of extending take-up of Direct Payments by disabled children's parents is considered to be central to increasing choice and control. Direct Payments can be made by a social services department following the assessment of an adult or child, so that the person (or parents of a disabled child) can arrange all or some of the care or support required. The money provided is used to employ the services of carers, and the flexibility this offers may be one route to improving the experience of families of disabled children. In 2002 only 270 families of approximately 29,000 disabled children receiving a service from social services in England were receiving Direct Payments (DfES, 2002a). Uptake of Direct Payments has been increasing, particularly since new guidance was published in September 2003 which made the offer of direct payments to families of disabled children mandatory in most circumstances.

Coordinating service delivery

It is clear from families' experiences that fragmented services can be disruptive to children and parents, and reduce the overall family time available for leisure and rest. For example, Heaton, Sloper, Roberts and Shah (2003) have highlighted from their

research with families with technology dependent children, that hospital appointments could be better coordinated with school timetables and parents' own schedules to minimise disruption overall to families. Service coordination continues to be prioritised within Labour Government policy for social care, health, education and welfare services:

Working in partnership is a key mechanism for delivery of services to children at risk of poverty and social exclusion in England through the Sure Start and Children's Fund initiatives. It is also prioritised in the National Service Frameworks for Disabled Children in England and Wales, with an emphasis on key working as a means of coordinating support for families.

(Abbott, Townsley and Watson, 2005, p156)

The Department of Health (2003) highlight that multi-agency working which is based on core understandings and processes should provide 'seamless' service to families which are responsive and supportive of inclusion (e.g. within communities, or specifically within a mainstream school setting). But whilst the development of multi-agency working (and, increasingly, integrated services) are key guiding principles in current service development, the Audit Commission (2003) have identified cultural barriers to different agencies working together. They reported that even when commitment to developing coordinated services was there, barriers existed in terms of systems, perspectives and resistance to joint working (even within agencies).

Perspectives on disability may be a barrier here. For example, the DoH (2003) have reported that lack of local data hampers agencies' ability to work strategically (separately and together), and that 'multi-agency databases containing core data on disabled children, including shared and agreed definitions' (p20) could improve the planning, commissioning and monitoring of services across the spectrum of health, social care and education.

When successful multi-agency working does occur, professionals have stated positively that this enables them to provide families with both coordinated services and better working relationships – although they also seem to be more able to express the benefits in their own working lives rather than in the lives of children and families (Abbott, Townsley and Watson, 2005). Research with disabled young people and their families broadly supports these current directions within policy. For example, Contact a Family report from a survey conducted in 2003 that access to a key worker, multi-agency working and the wide implementation of disability legislation within local services were key priorities.

In order to focus on the day-to-day childhood experiences and opportunities the review now turns to consider education and school based delivery of services, and opportunities to be involved in leisure (both within and outside school settings).

3.3 Education and Social Inclusion

Education provision, and non-educational (including multi-agency) services within educational settings, is increasingly recognised as central to the support and development that is required in ensuring social inclusion. Within this review, it is important to highlight the contribution of education to work with disabled children, both in terms of the delivery of teaching and learning, and in terms of the overall contribution to child, family and community well-being that the school can contribute towards. It is also important to acknowledge here that the childhood disability literature is not synonymous with work exploring 'special educational needs', and to be aware of the conceptual differences. Whilst it is not possible to provide an in depth review of the (broader) special educational needs literature, key concepts involved in policy debate and implications of school based practice for the social inclusion of disabled children are of value within this review. Inclusion itself as a concept has had specific meaning in relation to education and the support of children with special educational needs, and special needs, and it is important to consider the different use of language which exists in education-focused debate.

Special Educational Needs and disability

Since the introduction of education 'for all' in the late 19th century, children's needs have been characterised and categorised with reference to ability and disability, with corresponding consequences for the structural organisation of education and the delivery of teaching (e.g. see Copeland, 2003). This development of categorisation within the educational arena is relevant to the development of new understandings of impairment or disability, particularly those which are identified as having a cognitive or behavioural basis. This 'psychologization' of children and their development, explored by Van Drunen and Jansz (2004), presents as a largely clinical or medical model approach to understanding disability which is an important context to some of the 'special' education literature.

The specific concept of 'special educational needs' (SEN) was introduced as a legal term by the Education Act 1981, developed from the Warnock report (Department of Education and Science, 1978). This involved the abolishment of disability categories as organising features of educational provision to disabled children, and replaced this

with a focus on individual assessment of learning support needs, in recognition of the limited value of inflexible labels for understanding need. Thus SEN in some ways could be seen to challenge the 'disabled/non-disabled' categorisation of children which had previously occurred, with acknowledgement that levels of learning support needs could be better understood as falling within a continuum. The concept of SEN does require differentiation from 'special needs' which instead refers to children's needs that arise out of membership of a specific social group: e.g. in relation to language, culture, experience of racism, experience of socio-economic disadvantage. Whilst SEN and special needs are often used interchangeably, we can see that when used with precision there has been an attempt to differentiate between individual developmental needs, and socially derived needs (for an introduction see Frederickson and Cline, 2002).

SEN itself can also be experienced as a negative label which suggests within-learner deficit and difference (Dyson and Millward, 2000), rather than diversity amongst children in relation to both impairment and social experience. It is important to note, however, that responding to diversity is increasingly being stressed within the development of educational strategy in this area, with reference to understanding underlying causes of difficulties beyond impairment (including social and economic deprivation), (e.g. DfES, 2004).

The interchangeable use, or imprecise use, of SEN and special needs could be seen to mirror difficulties in wider practice and debate between use of 'impairment' and 'disability', and the importance assigned to addressing individual need or social organisation. There are clearly differences between education and disability based work in the concepts most often used to understand individual need, and difficulties both within educational and disability related debate concerning attempts to differentiate between individually derived needs and socially based ones. These differences in language can clearly create difficulties in joint working. For example, the Council for Disabled Children (1999) report that there were definitional difficulties in relation to 'disability' and 'SEN' in local authority responses to Quality Protects. They indicate that this can have implications for the collation of data and for developing information on the use of services by disabled children. There are also corresponding difficulties that arise in trying to connect service development for children with SEN and disabled children. Having reviewed selected Management Action Plans within local authorities, the Council for Disabled Children reported that:

Disappointingly there was no reference to the potential use of data on children with SEN held on LEA registers for developing more reliable management information on local populations of disabled children. This lack of joint planning appears in part to relate to concerns about definitions of disability and SEN and potentially different pathways for assessment and provision.

(Council for Disabled Children, 1999, p14)

There is a tension here between the possible organisational benefits of coming to prioritise a specific definition of need, and the value of having different frameworks (e.g. disability; special educational needs) which could be viewed to be complementary. What is clear is that definitional issues and understandings within policy development and practice have implications for the organisation and delivery of services, and particularly for multi-agency approaches. In addition, a holistic understanding of children's needs (beyond any specific professional interest in either pupil, social work client, or patient-related needs) is required if agencies and practitioners are to be able to engage with each other on the delivery of services (Petrie, Storey, Thompson and Candappa, 2003), or support parents with appropriate advice and signposting. For example Preston (2005) has highlighted through research that families whose children have a statement of 'special educational needs' may not have been informed about their child's potential entitlement to Disability Living Allowance. This in part could be seen to be due to the different 'welfare categories' currently involved in characterising the needs of children and families.

Education, disability and inclusion

The outcome of the Warnock Report (DES, 1978) was an understanding that the delivery of services to children with SEN could be placed on a continuum, rather than having a fixed approach to delivery as either 'mainstream' or 'special'. Provision for disabled children and children with SEN was developed whereby resources and services to support children with individual learning needs could be provided within mainstream schools: thus integration (where children considered to have SEN enter unchanged mainstream schools), and then inclusion (whereby schools respond to the diversity of the needs within the community served), became particular responses that sought to develop more diversity within schools and less segregation (Dyson and Millward, 2000). Some writers have argued the resulting organisation of education could be understood to be 'systemic dualism', whereby both inclusive education and special education co-exist (Swain, French and Cameron, 2003). 'Special' educational delivery to disabled children remains a high profile issue, for example as developed within recent policy debates during the 2005 general election.

Whilst the debate can be polarised (e.g. with different education and disability relevant organisations stressing the value of either special or inclusive education), others support the current policy of a continuum of services (e.g. PACE, Spring 2005). The case for inclusion and challenges to it need to be understood within the specific context of a rapid reduction of special school provision. As Barton (2003) stresses, the move from segregation to inclusive provision requires careful planning and implementation, and in the current situation some parents prefer their child to attend a special day or residential school. This is not, he argues, a specific defence for special school education but instead identifies the limitations of 'ordinary' schools which have been unable to provide a fully inclusive environment. So whilst it could be argued that a special school that may be well equipped to meet impairment related needs yet further disables a child by stressing what is 'different' rather than shared, in fact poor 'inclusive' practices could be even more damaging for some children.

Davis and Watson (2001) have conducted research that has been concerned to identify some of the nuances involved in enabling inclusion in education, by focusing on the experience of children in the context of the specific cultural and inter-personal practices between adults and children within both 'special' and 'mainstream' settings. This research found that whilst structural barriers are often the focus of attempts to support inclusion, in fact the inter-personal reiteration of 'difference' by adults to children in any school setting is supported by specific discourses around disability and special educational needs, poor resources, and a lack of training and support for teachers in challenging disabling practices. They also identify that teachers often wish to work in an inclusive manner but face barriers to doing so.

The extended school and inclusion

Whilst the provision of both inclusive and 'special' education are relevant to understanding of social inclusion for disabled children, so too are the general developments being enacted in school-based services as a whole. Extended schools (e.g. see DfES, 2002b) are one potential way of ensuring that non-stigmatising services are offered to disabled children and other non-disabled children and families who require support or advice. The availability of services within school environments may also improve accessibility as well as professional knowledge and understanding concerning the range of provisions available. As Axford and Little (2004) note, children and families with social needs first of all turn to the services they currently engage with. In reviewing the available literature on preventative services for all

children, they also note the success of school based mental health and health improvement programmes in the United States. Such research suggests that schools are likely to be important in the development of integrated services.

But how are school based services experienced, and are there any current difficulties or obstacles identified? Research suggests that school-based leisure activities are often greatly valued by parents of disabled children and by children themselves. These are, however, currently often limited to the term time period with a resulting gap in leisure provision during school holidays (Petrie and Poland, 1998). In addition, some parents have expressed mixed feelings about the provision of play services at school considering that some children and young people would not want to necessarily return to school for leisure based activities (DoCMS, 2004). Clearly these findings are of interest in the current climate where the school as a place is being expanded in terms of services provided, which may subsequently strengthen their overall connections with local communities.

3.4 Leisure Services and Social Inclusion

We have previously seen that a significant concern amongst disabled parents and their families in relation to housing is the lack of space within the home for their children to engage in play, and that this should be considered an important part of any assessment of housing need (Beresford and Oldman, 2002). For services providing leisure and play opportunities to children, the particular problems posed by home environments for day-to-day leisure and play might be an important context to understand children's (including disabled children's siblings') support needs. Engaging in leisure activities beyond the immediate home environment can be an important element of participation in local communities. A lack of opportunity to engage in activities away from the home may be linked to the lack of resources (emotional, physical, and financial) in the immediate household and amongst relatives and friends.

Aitchison (2003) identifies the positive potential impacts of leisure as important in:

- Increasing self-esteem, confidence and psychological well-being.
- Enhancing physical health and fitness.
- Reducing the risk of illness.
- Contributing towards positive social interaction and relationships.

Play and leisure can be understood to be central to children's self-development in terms of practical, social and emotional skills, knowledge and understanding. Even without headlining tightly defined positive outcomes, leisure and play for their own sake are important ways for children to express themselves and experience self-determination.

As we have seen the right to leisure and play is a recognised human right within the UN Convention on the Rights of the Child, but whilst there are improvements in provision it continues to be identified that disabled children face barriers to access of both specialist and inclusive leisure activities, (e.g. Audit Commission, 2003). These barriers may include topographical aspects of the physical environment, planned and man-made features of streets and parks, and the nature of public play equipment. Attitudes of parents, disabled children, and other adults and children might also be restrictive (e.g. because of concerns about risk) and/or discriminatory. Jenkins (2002) has highlighted that restricted leisure opportunities for many disabled children may be due to the compound effect of low family income and concerns about injury and appropriate spaces. Additionally, specific resource difficulties (such as lack of funding for services, including availability of trained staff) have been found to affect access to and the provision of inclusive local authority services: this can especially be the case for older disabled children given that there are less facilities available for older children as a whole (Petrie, Storey and Candappa, 2002).

Playgrounds and outside spaces for spontaneous play

Jenkins (2002) highlights the strong case for prioritising play space as central to disabled children's lives:

Advocates of play spaces for disabled children argue that their inclusion in play opportunities is a basic human right as the exclusion of disabled children from play spaces prolongs their dependence on parents and other primary care-givers for leisure and recreational activities. It also denies disabled children the opportunity to socialise with their non-disabled peers.

(Jenkins, 2002, p4)

The developing awareness of access issues in relation to disabled children's play, the implementation of the Disability Discrimination Act 1995, and the development of a generally inclusive strategy within England to build up opportunities for play demonstrate that action is being taken here. For example, children's leisure services are now expected to make 'reasonable adjustments' under the Disability Discrimination Act 1995. It has however been suggested that some authorities and

organisations might feel paralysed or uncertain about how to proceed. This might be a result of being concerned to meet the needs of all children (which may not be possible within one play space), and sometimes looking to always 'start from scratch' with playgrounds, instead of looking to make 'reasonable adjustments' to existing spaces:

... there is much advice on how to create very expensive playgrounds and [...] Local Authorities and other providers were concerned that pressure to adopt this type of advice, to comply with the DDA, could lead to a significant reduction in play opportunities for all children.

(John and Whewey, 2004, p4-5)

John and Whewey (2004) observed disabled children playing in playgrounds (within their special schools, and also public playgrounds), and then interviewed some parents within their own homes. They speculated that the use of public spaces and playgrounds by disabled children can be determined by a broader range of factors than the design of these spaces themselves. Parents' beliefs about what provisions are 'appropriate' for their child, their fears, and the attitudes of other children using these spaces, are also important considerations. Clearly expensive modifications to playgrounds which do not attract disabled children are not going to create actively inclusive spaces. John and Whewey (2004) further highlight the importance of Disability Equality Training which could assist youth and play workers, and others, to help support the confidence of parents and children and help build relationships at playground sites.

Leisure activities outside the home

Of crucial importance to disabled children's social inclusion is their own and their families' ability to access mainstream leisure facilities. Shelley (2002) reports on survey research conducted by Contact a Family with over 1000 parents of disabled children across the UK. Shelley's research identified that many parents felt that there were barriers to even beginning to consider accessing leisure facilities. For nearly half of respondents limited outings were linked to lack of funds, and for a quarter lack of transport was a factor. Some barriers were directly related to impairment – for example distress experienced by a child if required to queue. Queue -'jumping' schemes, for instance offered at some leisure parks, were valued: however, even when needs arising from impairment are recognised in this way, one parent reported an attitudinal barrier: *Even on queue jumping schemes one has to undergo abuse and hurtful comments from the public which spoil the day for all.*

Other attitudes causing discomfort and preventing access were identified:

There are no pictures ever of anyone with a disability so that anyone who reveals a non-standard issue body in their swimsuit gets stared at ... the public needs to be educated...

Our son has severe learning difficulties with no communication and inappropriate behaviour. We are prevented from using facilities because other people do not accept our son's reactions.

[All three quotes are parents reported by Shelley, 2002, p5]

Shelley (2002) also reported that physical features were important, and were identified in relation to a wide range of leisure activities. From playgrounds and parks to bowling alleys, pools, theatres and so on, availability of disability facilities were often a specific consideration. For example, whether or not there was adequate disability parking (most often referred to in connection with theatres, museums and playgrounds), or accessible toilets (particularly at football matches, playgrounds and parks) could restrict family outings.

Play scheme provision is a specific resource which disabled children and their families might value. Petrie and Poland (1998) studied, via semi-structured interviews, mothers' satisfaction with both specialist and 'mainstream' play services for their disabled school-age children. Children within the families selected represented a range of impairment experiences and a wide spectrum of severity of impairment, although many had complex needs. Overall high levels of satisfaction were expressed with all play services being praised for providing an additional resource for the family (and thus reducing stress for parents). Specific benefits identified for disabled children from play activities included being with other children, having space for self-expression, and developing skills.

Play services are strongly valued by families who use them, but accessing them is clearly difficult for many families which include a disabled child. A lack of affordable, accessible and inclusive activities can significantly restrict disabled children's involvement with other children throughout the year, but often this is most noted during the long school holidays. Sharma and Dowling (2004) identified that projects which can (or try to) attract funding face a range of difficulties given their high costs (including staffing needs) and lack of appropriate premises. They also spoke to disabled children and to some siblings about their specific experience of the summer holidays. They found evidence that insufficient financial resources, inaccessible and

inadequate facilities and negative public attitudes were all implicated in exclusion from summer leisure schemes.

‘Special’ or mainstream opportunities?

There is mixed evidence on whether, how or when special provision for disabled children is able to support young people’s development and contribute to inclusion. An important context here is the child’s experience of either mainstream or special education and the ways in which this might be networked to other opportunities for leisure. It is also important to consider the ways in which some disabled children’s days may be regimented (e.g. by educational and other transport provisions; the location and organisation of medical and other therapies) and geographically fragmented, leaving less space available for play. Petrie and Poland (1998) identify that for parents whose children attend special schools, these schools may not know about opportunities local to the child’s home for play services and so access would more often be dependent on social work contact, informal networks, and/or self-referral. John and Whewey (2004), who exclusively looked at the experience of children attending special schools, identified travel time to school, lack of opportunity to see friends outside of school, lack of contact with children living more locally, and parent’s lack of contact and experience of ‘neighbourliness’ with other local parents and families. A solution suggested was for all disabled children to be offered the opportunity of regularly visiting, and taking part in activities at, their local mainstream school. The development of extended schooling may provide greater opportunities for this in the future.

With specific reference to leisure, Action for Leisure and Contact a Family (2003) identify ‘special’ versus ‘mainstream’ as a tension amongst parents, for whom ‘inclusion’ however defined is a central and emotive issue. Some parents involved in their study felt that inclusive provision was key, and the only way in which the range of opportunities their child required could be met. For others, and particularly for parents of children with severe / complex needs, specialist settings were often preferred for the individual support and expertise available. Action for Leisure and Contact a Family (2003) identify inclusion as being about an ‘attitude of mind’, and this can be understood when we try to identify exclusionary practices.

Interestingly it seems that approaches take on slightly different forms when they are about either clubs (where special provision is sometimes valued) or use of public space (where inclusion agendas are most clearly agreed). The ODPM (2004b)

highlight inclusive play spaces for disabled children and their siblings as key to social inclusion within communities. John and Wheway (2004) argue (with direct reference to playgrounds) that segregated spaces are exclusionary and should no longer be developed (except where they are primarily concerned with therapy/development instead of child-led play). They argue clearly that they have in the past been developed to keep disabled children invisible, particularly for adults who find impairment uncomfortable to acknowledge. Turner's (2003) consultation work with young disabled people (aged five to 25) provides evidence of positive experience of special facilities and events. Turner states that 'the majority of disabled children and young people feel most comfortable attending leisure services exclusively for disabled children' (p50). Young people of course did express different preferences, with some preferring to be with all their family, and others preferring to have time doing their own thing away from siblings and parents. It is important to note, however, that many such 'exclusive' services may actually involve non-disabled siblings. Rees (2002) identified that parent-support group led services tended to focus on play and leisure, and often provided 'support to siblings' such as inclusion in leisure activities (as well as sibling support groups and referrals to 'young carers' projects).

Access to well-resourced inclusive clubs and facilities are discussed by Shelley (2002), who identifies the difficulties faced by parents wanting their children to be able to access a range of mainstream clubs, but facing an 'option' of one 'special' club. Young people attending 'inclusive' leisure provision often stated that parents or siblings would be involved in actively supporting their involvement which could sometimes mean that disabled children did not receive opportunities for leisure away from their families. Conversely, Sharma and Dowling (2004) found that there was a negative impact on families where siblings were segregated in their activities because of disability:

Many families with disabled children also have other children: Generally, siblings cannot participate in the same social activities as their disabled brother or sister. Both children and their parents find this very excluding. Parents feel very strongly that services must be inclusive to support brothers and sisters who have a disabled sibling. Young carers' groups are a good source of support, but places are in short supply.

(Sharma and Dowling, 2004, p12)

This seems a little unclear as young carers' groups are not a form of inclusive service in and of themselves particularly if disabled children are not included. Sharma and Dowling (2004) did identify that siblings of disabled children often had experience of

others' negative attitudes towards their brother or sister which might highlight a need to meet with others who have also experienced this. More broadly, they recommend that Local Authorities' assessment of leisure strategies for summer holidays should 'take account of the needs of non-disabled siblings, so that they can be included' (p 4).

Barriers to leisure and play opportunities are of course relevant to both disabled children and their siblings, and research conducted by Contact a Family (Chandler, 2003) identifies leisure as a central concern for disabled children, their brothers and sisters, and their parents. Chandler highlights a need for a strategy around leisure services in Birmingham, providing key funding priorities for those funding the voluntary sector. This research involved innovative methods in terms of consulting disabled children and their siblings. Interviews with individuals and small groups were built around children's development of picture representations which showed the activities they wanted and did not want to be involved in. The priorities developed were as follows:

- A directory of mainstream and special needs sports facilities which include and welcome disabled children.
- A guide to accessible and good days out for families of disabled children.
- A website with up-to-date information on accessible and inclusive clubs and facilities.
- Specialist swimming lessons to support disabled children to use mainstream pools.
- Family fun events for disabled children and their families.
- Training for leisure staff on working with disabled children.
- Accessible parks and playgrounds, and supervised parks and playgrounds.

Research concerning leisure activities outside the home highlights areas for development for government (including Local Authorities) and for the voluntary sector. As well as structural and material resource needs, the research once again highlights inter-personal features of disability involved in the debates concerning specialist responses versus inclusive approaches. And whilst there are some tensions identified above between the needs of individual disabled children and their families, family support does require some further in-depth consideration.

3.5 Family Support

The whole family is vulnerable to social exclusion. Parents may experience employment problems because of caring responsibilities. They have little time to themselves, and often miss out on holidays or even free evenings. Siblings sometimes feel restricted in taking part in everyday activities by the needs of their disabled siblings or by public attitudes towards them.

(Audit Commission, 2003, 25)

In discussing the impact of disability on the disabled child *and their family*, the Audit Commission highlight the ways in which the whole range of service areas are important in preventing the social exclusion of all family members. Our earlier discussion of the impact of low family resources and restricted living spaces clearly has implications for all family members (e.g. as considered by Oldman and Beresford, 2000). In addition, different individuals may have different needs – and even different interpretations of needs – which make whole family support a less than straightforward issue.

The delivery of specific services to disabled children without addressing other individuals' needs may marginalise some family members (Beresford, Sloper, Baldwin and Newman, 1996) and perhaps especially fathers, as supporting parenting has often been equated with supporting mothering. For example, Britton (2001) found that fathers of disabled children (who had arthritis) were in particular need of more support and information. West (2000) also identified within her small-scale qualitative study that fathers of disabled children felt a particular need for more information and for someone (i.e. a particular worker with knowledge and understanding) to talk too. Mitchell and Sloper (2000) further reported from their research with parents and professionals that information about support for the whole family was particularly valued, and in relation to an information resource, one professional stated that:

I have to stand up and give a clap to Somerset [Finding Your Way] which was very good factually and I found for the first time ever DADDS [Dads and Disabled Daughters and Sons] in it ... they often get lost in the milieu, the dads coping with disabilities.

(Professional view reported in Mitchell and Sloper, 2000, 31)

A specific issue here is the way in which assessments focus on individual need or succeed in taking a family-aware approach. Mencap (2001) conducted interview and focus group research with parents whose (child and adult) children had learning disabilities and reported the following:

Parents... felt that the assessment process does not take account of their needs when assessing the needs of their son or daughter. Families were not informed of their entitlement to an assessment of their own needs under the Carers Recognition and Services Act 1995. Many families claimed that there was no suitable respite available to give them a break from caring. Few assessments took account of the needs of wider family members and their circumstances....

(Mencap, 2001, p27)

Burke (2004) expands on this theme, identifying a whole-family based approach to full assessment, where children are all included and time is allowed for all people's needs to be expressed and recorded. Following (full or narrow) assessment, services delivered may be ambiguous about the extent to which they are available as family support or individual disabled child related support. Olsen and Maslin-Prothero (2001) identify that parents reported inconsistent approaches within one 'own-home' respite service for parents of children with complex health needs. Parental reports suggest that in some families the service could be involved in looking after non-disabled siblings alongside the disabled child (enabling parents to recharge batteries, have space, and pursue another activity and so on). Other families were told that it was not possible for Outreach service staff to look after healthy or non-disabled siblings, and this meant that some families had not used the service as a result. Whilst there was no space within this review to include more clinically orientated research, it is important to note that there is evidence from clinical and psychological research that would support the importance of a whole family approach, that could acknowledge the import of the family as a system which can support young people's resilience when faced with difficult situations (e.g. see Williams, 1997).

Siblings and family support needs

The shared needs and individual needs of children, including non-disabled siblings, ought to be considered when developing and providing services to families (Ratcliffe, 2003). We have seen earlier – in relation to leisure – some specific examples of how disabled children and their non-disabled brothers and sisters will share needs and wants, and also may have different needs arising from one sibling's disability. In relation to housing difficulties restricted space may lead to different difficulties for different family members (e.g. restricted personal space; disrupted sleep). Oldman and Beresford (2000) provide the following example that illustrates the inter-personal and developmental issues involved:

Siblings suffered from lack of space. There were a number of instances of siblings being adversely affected by not being able to get away from the disabled child. One mother, for example, felt that her eldest son's

psychological difficulties were attributable to the fact that there was never enough room for him to escape the attention of his autistic brother who frequently destroyed precious artwork.

(Oldman and Beresford, 2000, p473)

Oldman and Beresford present this in the context of an understanding of the impact of environment on children, and consider that difficulties could be individualised by professionals, instead of being understood in social space and inter-personal terms:

The feelings of low self-esteem felt by children (disabled and non-disabled siblings) tended to be medicalised by professionals. There is a case to be made however that these feelings were induced by space restrictions and that these are health and housing problems addressed by housing intervention.

(Oldman and Beresford, 2000, p438)

Psychological distress has been highlighted elsewhere, for example by Rees (2002) who stressed how much parents said that sibling children valued sibling support groups. Space to discuss and work through difficulties within the family's day-to-day life, away from other family members, was seen to be valuable (sometimes alongside whole-family leisure opportunities):

Organisations, which offered a Sibling Support Group, gave children the chance to make contact with other siblings of disabled children, where they were able to express their feelings without suffering mockery or bullying by their more 'mainstream' peers. Parents also reported that siblings also valued the opportunity of being involved in social or leisure activities their disabled brother or sister had access to.

(Rees, 2002, p22)

Warren Dodd (2004) provides further research evidence on sibling support in her report of a group run for brothers and sisters which was considered valuable in providing a break away from the family, opportunities for developing friendships, and developing independence skills. 'Young carers' groups can also be viewed as sources of emotional support, or of opportunities for fun away from 'the pressures of caring' (e.g. Watson, Lewis, Townsley, Abbott and Cowen, 2004). Ward (2001) considers that siblings' needs should be specifically addressed by services, and that children whose brother or sister has a learning disability may themselves have specific needs:

... the emotional needs of siblings have been neglected and young carer's projects tend to focus on the needs of those caring for a parent. The long-term consequences of having a sibling who has a learning disability need to be explored and appropriate support offered.

(Ward, 2001, p21)

Limited finances may clearly impact on the opportunities available to all children in a family. Preston (2005) reports that some parents were concerned that their non-disabled children could feel that they have to 'come second', and being able to 'treat' children (e.g. by providing an allowance, or by ensuring a party can be given at a birthday) had powerful personal significance when parents were concerned that each of their children in the long-term were 'losing out'. Preston strongly demonstrates the impact of reductions in DLA (Disability Living Allowance) payments when children's needs have been reassessed. For example, less opportunities to go out (and so more social isolation at home), being less able to produce rounded meals, and feeling that the options available for support could equate to becoming limited to 'begging' for charity, could each be distressing and felt to be humiliating.

The experience of disablism for both disabled children and their siblings has been explored by Connors and Stalker (2003) and Stalker and Connors (2004). Their research highlighted that siblings were impacted emotionally by observing the disabled sibling being excluded, or through personally being marginalised and attacked by others. For only a small number of non-disabled children the 'lens' of impairment was primary: for most non-disabled siblings, the disabled child was clearly foremost their brother or sister, sharing family biographies and involving 'normal' sibling qualities within relationships, such as love and rivalry.

Siblings have also been identified as providing support within the family, on a continuum from general involvement in child care and household chores, through to increased involvement which might be considered to be a 'carer' role. Heaton, Noyes, Sloper and Shah (2003) explored the experiences of 36 families which included a technology dependent child. They identified that brothers and sisters were involved to varied degrees, with some young people involved in 'technical' aspects of care (i.e. supporting the young person's use of a medical device). Medical-related support needs may have specific impacts on families, including other children. For example, research by Townsley and Robinson (1999) has highlighted the impact of home enteral tube feeding [HETF] on family life:

Parents found that caring for a tube fed child with complex needs was an emotionally and physically demanding experience. Social isolation, regular night disturbance, and feelings of guilt about accepting HETF for their child were issues described by the vast majority of parents we interviewed. Some siblings were playing a significant role in supporting their tube-fed sister or brother.

(Townsley and Robinson, 1999, p4)

Interestingly, Townsley and Robinson go on to highlight to professionals that they should look out for signs that siblings are becoming young carers, and where this is observed they should 'offer appropriate support'. What is not clear from this is whether appropriate support is increased paid carer support, or 'young carer' group support, or both. Whilst 'carer' focused approaches in research and policy *can* provide complex and flexible account of needs and experiences, the more partial understandings that can emerge are problematic. For example, from a 'carer' perspective, siblings of disabled children may be identified and primarily understood as 'young carers', rather than as brothers or sisters (Banks, Cogan, Deeley, Hill, Riddell and Tisdall, 2001).

Of course, disabled children sometimes have disabled siblings too. Lawton (1998) analysed the numbers and characteristics of disabled children with more than one disabled child, and estimated that there were 17,000 families that included more than one disabled child in the UK with 6,500 estimated to contain more than two severely disabled children. Lawton identifies that assessments (e.g. for benefits) often do not take account of the cumulative costs of care, and so many may 'miss the threshold' for a level of support based on two individual assessments (which might not have occurred if a whole family approach was taken).

3.6 Conclusion

The development of services for disabled children has been contextualised in relation to the family home and resources, and many of the material and structural barriers faced by families are identified within the research literature. Current directions in service development and delivery are importantly being shaped by the implementation of existing disability discrimination legislation, and with reference to children's rights. The full breadth of policy as regards services for children (including educational policy and child care policy) is of direct relevance to the experiences of families of disabled children, and the abilities of services to develop and provide joined up services. Some of the research suggests that there are training needs and resource needs to support service development, for example in increasing the amount of inclusive and accessible leisure services for children. The research also suggests that the specific needs of families which include more than one disabled family member should be considered within the development of services.

The complexity of family life, and the ways in which a fragmented organisation of services can exacerbate stresses within the family, are increasingly recognised within

policy. Currently strong moves towards multi-agency working are being developed, although there are barriers faced within this process. Some of these barriers are specific to disability, and this includes issues concerning definition and discourse in the understanding of disability and need.

Clearly responses to social exclusion need to challenge inter-personal elements of disablism as well as physical and material barriers. And whilst the value of 'whole family' approaches to assessment and provision of services have been shown to be important in ensuring inclusion, an awareness needs to be maintained that individuals within families can often have different and competing needs and wants. A significant challenge for all providers in the move towards more joined-up provision is the creation of services which are sensitive enough to respond to this, and in particular to take on board the disabled child's perspective.

Chapter 4: Reflection on the Literature

4.1 Introduction

In Chapter 1 the social model of disability and human rights claims to social justice were identified as key contexts for the review of both research and policy. This review has necessarily involved a consideration of material from a variety of research agendas which highlight the range of support issues involved when trying to prevent exclusion amongst this group of children and families.

Here a brief reflection is made on the nature of the arguments presented and perspectives taken which are relevant to the approaches taken within policy and by services.

4.2 Agendas in Research and Practice

Children first

Both disability researchers and sociologists of childhood have identified the ways in which research has often excluded the voices of disabled children, and therefore has not upheld their rights, nor recognised their aspirations: this is particularly a criticism levelled at medicalising / impairment based approaches. Disabled children's parents' involvement in research (e.g. through participation as respondents or as researchers) has expanded our ability to take a whole family approach, and yet there can also be concerns that *over*-reliance on parents can ignore and exclude the child's view (Shakespeare, Barnes, Priestley, Cunninghambirley, Davis, and Watson, 1999). Similarly, a focus on the experiences of siblings as 'young carers' may provide important space for the experiences of some young people to be heard, but may marginalize the disabled child and present a highly dependent portrayal. A fragmented conceptualisation of the different needs within a family can identify tensions between these different needs (for instance, if limited to a focus on a disabled child's impairment or family members' 'carer' roles). We have seen that, in the context both of the social model conception of disability, and of human rights based claims, disabled children's rights as children are increasingly being articulated by parents, young people, and within service standards.

Dynamic approaches

As Priestley (1998) argues, disability studies can provide invaluable insights to the exclusion of disabled children. Consideration of the experiences of disabled children in family context demonstrates that a limited concern with current barriers (i.e. a

surface or static application of a social model approach) could be in danger of providing a restricted analysis, either in terms of a focus on the individual (child) rather on the child in their family's relational and socio-economic context, or in terms of not providing a consideration of change over time.

This is a debate which is reflected within disability studies and within policy research. For example within Thomas's (1999, 2004) exposition of a sociologically grounded 'relational perspective' to understanding the social imposition (at a micro and macro level) of barriers to 'being' and barriers to 'doing'. This argument highlights early (but often-since overshadowed) interests in disability studies which considered inter-personal factors to be central, including the power relationships between disabled and non-disabled people. It provides a clear definition of disability as the socially-imposed barriers experienced by people who have impairment (distinguishing disability from 'impairment effects'). Thomas's barriers to doing can be equated to issues of access, whilst barriers to being are related to the emotionally debilitating effects of inter-personal, organisational and cultural hostility. In relation to the enabling of disabled children, and understanding this within a life-span developmental perspective, challenging cultural and inter-personal practices that are 'barriers to doing' and 'barriers to being' may offer a valuable way to conceptualise the development of inclusive organisations and ways of working. This perspective may also support the strengthening of research concerned to understand disabled children's (and their families') experiences as social actors, for example in terms of their interpretation of and challenging of the barriers encountered.

Additionally, from their valuable research with 240 disabled children and their families, the Audit Commission (2003) state clearly that a temporal perspective is required to understand and respond to inadequacies which impact on child development and well being:

It is self-evident that children grow, move through developmental stages and become adults. But families felt that this was not fully understood in the ways service were planned and delivered. Waiting for treatment or equipment was a universal experience for the families we spoke to. For example, we found year long waits for a speech and language assessment followed by a further lengthy wait before the service was actually delivered. Waiting for equipment often meant that children had outgrown it by the time it had arrived. We found little consideration of age-related preferences, or of young people's developing sense of self and social awareness. In many cases families faced the choice of using a service where their child felt out of place because of their age, or not having a service at all.

(Audit Commission, 2003, p6)

This more dynamic and responsive mode is posed as a 'Leadership Challenge' by the Audit Commission. This is highlighted again within a guidance materials booklet on support for siblings which flags up the importance of 'access to lifelong and continually changing information' whereby siblings receive updates on their brother or sister's disability which is age appropriate (Sibs, 2004). Dynamic and age-appropriate responses to disabled children and their families are also clearly relevant to the current Governmental development of a life course approach to improving disabled people's life chances (PMSU, 2005).

4.3 Summary of Key Messages for NE-CF

i. Whilst disabled children and their families may face specific barriers to social participation and inclusion, the needs of disabled children are often the same as the needs of other children

Many disabled children's experiences may be shaped by problems relating to poor environments and a lack of family resources. The organisation and provision of services for disabled children should be conducted with reference to the resource limits faced by parents, and resources within the local community. The implications of strategies to combat child poverty for families that include a disabled child require specific examination.

ii. Tackling exclusion of disabled children and their families involves but is not only about ensuring inclusion in public spaces

The quality and appropriateness of the private home environment may reduce the quality of life of all family members. For example, opportunities for play, leisure and social engagement may be restricted within the home with implications for individual happiness and well being (including health implications). Further, the home needs to be considered as a base from which all family members can develop relationships with each other and with local neighbours and friends. Access to supports that can ensure that child care can be provided in others' homes is also important to many families.

iii. Inclusion needs to be considered with clear reference to children's key relationships

A whole-family approach requires that a disabled child's needs are understood within the family context, and that involves identifying the needs of all parents and children

(including the shared needs, e.g. for family time and independent time). Challenging inter-personal aspects of disability, such as disabling attitudes, are also highlighted as important in challenging social exclusion. Disabling attitudes may be experienced by the disabled child and by other family members.

iv. The Disability Discrimination Act 1995 (and subsequent related disability legislation) provides a key context within which to support the development of services

As an important example in relation to play and leisure, research suggests that disability information and training for those developing local policy and provision is an ongoing need, particularly given the heterogeneity of disabled children as a group and the wide range of access issues that can often be involved. A further challenge, not reviewed in-depth here, concerns the involvement of disabled children in service development activities (Badham, 2004; Cavet and Sloper, 2004).

v. Education provision for children has clear implications for their social inclusion within the community

Access to involvement within local mainstream schools as school pupils, (or when specialist school provision is instead received, as visitors) could be a way of improving local social networks for parents and children. This may be possible to support further within the development of extended school provision. Schools as inclusive community spaces, and potentially as sites for multi-agency service provision, may improve the availability of information for both parents and professionals.

vi. Inclusion for this age-group is often explored with reference to education, and this is an important structuring feature of children's lives which needs to be considered alongside other factors within the home and community.

Whilst education is important, a greater focus is required on children's experience away from school, including the ways in which different types of school provision can impact on the experience of living within the wider local community. Whilst there is clearly potential value in the development of extended school services, some research evidence identifies that for some children community (rather than school) based services may be preferred. This may in part reflect some young people's negative experiences at school which should be further explored, and may in part be

addressed if they are able to continue to become more (structurally and culturally) inclusive spaces.

vii. Multi-agency working is identified as key by both professionals and parents, and this requires the development of shared understandings

There are barriers to multi-agency working (such as perspectives on disability, definitions, and disputes about professional roles) which require head-on consideration in service development. In particular, 'special educational needs' and disability are different concepts, which may be valuable and complementary, but reflect different discourses in educational and social care provision. Children's rights, support for 'carers' and family support all offer different types of solution to difficulties faced. In relation to support for parents and for siblings, 'carer'-based responses to need may be valuable sources of support and yet may miss crucial aspects of the ways in which all members of the family can face disabling barriers. Understanding the different discourses and concepts referred to throughout policy and provision relevant to disabled children is vital in the development of multi-agency approaches to tackling social exclusion.

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