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Centre for Public Health Research

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Executive summary

Introduction

Providing support for parents to enable them to bring up their children has emerged as a prominent theme of current social policy. However, recent research has shown that disabled parents face considerable obstacles in trying to access services to support them in meeting the day-to-day demands of being a parent.

This study explores the experiences of disabled parents in Cheshire in order to represent accurately disabled parents' perspectives on their experiences of using local services. The study has the potential to inform local providers and advocacy groups about the strengths and weaknesses of local provision as well as provide them with an evidence base from which to work towards improving local provision.

Study design and methods

The research was commissioned by Cheshire Disabilities Federation and funded by Cheshire Children's Fund. It was guided by a steering group, the Disabled Parents Steering Group. All aspects of the research project were discussed and agreed with the Steering Group, particularly those aspects that related to the development of the research instrument – the questionnaire – and the recruitment of research participants. In order to explore disabled parents' experiences the study used a series of in-depth telephone interviews with disabled parents. Overall, 16 disabled parents took part in the study.

Findings

- Overall, disabled parents' experiences of local services were mixed, with some examples of good practice but also some examples of practice that undermined parents' capacity to carry out their parenting role.
- Direct payments were seen in a very positive light, but some parents reported that they did not know about direct payments or, if they did, they had reservations about using them.
- Disabled parents reported difficulties with all public services – health, education, and social services – but there was some evidence to suggest that local leisure and social activities were less of a problem.
- Using the social model of disability, difficulties were categorised in terms of structural-environmental and process factors. In terms of the former, these

primarily related to access to buildings, facilities and information, as well as difficulties with transport. In terms of the latter, these primarily related to practitioner knowledge, skills and predisposition to engage responsively and flexibly with disabled parents.

- Disabled parents also reported being fearful of public sector organisations in that they felt their capability and capacity to parent their children was questioned automatically simply because they had an impairment.
- Taken together, these factors meant that many disabled parents were socially excluded from fully participating in their children's lives.

Conclusion

The findings from this small-scale study point to the need for systems and services that are more responsive to the diverse needs of disabled parents and there are a number of tangible steps that could be taken to challenge the prevailing climate in which disabled parents have to fight for various entitlements.

- Direct payments can be seen as a genuinely empowering policy development. All those who are entitled to direct payments need to be routinely informed about them, have opportunities to discuss their concerns and be supported appropriately when they embark on the process of applying for them. The routine use of the disabled parents' assessment tool developed by Cheshire Disabilities Federation might be a valuable means of supporting parents through the assessment process.
- To avoid the separation of disabled parents' personal needs from those of their families, the community care assessment process should be framed in terms of a *family-centred* assessment. It is likely that this will be a more effective and efficient process for all parties since it is more likely to mean that a holistic assessment is carried out.
- There is potential to shift professional practice in a more disabled-aware direction if attention is given to staff development and training that prioritises disability-related knowledge, skilled assistance and the management of social relations based on dignity and respect. It is likely that this is one of the most important factors if responsive and flexible services are to develop as well as being the means by which social norms are challenged.
- The designation of key staff with responsibility for disabled parents in organisations might be a beneficial development.

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- There is a key role for the voluntary sector in facilitating change. Organisations, such as Cheshire Disabilities Federation, are in the best possible position to advocate on disabled parents' behalf; by engaging with local public sector organisations they can be the voice for debating how best to take the agenda forward in a way that best serves the interests of disabled parents and their children.

Chapter 1

Introduction

1.1 Background and context

Providing support for parents to enable them to bring up their children has emerged as a prominent theme of current social policy. However, recent research has shown that disabled parents face considerable obstacles in trying to access services to support them in meeting the day-to-day demands of being a parent (Goodinge, 2000; Morris, 2003; Tyers, 2001; Wates, 2003). Whilst services are available to meet their individual disability-related personal needs, receiving support to enable them to undertake their parenting role is much more difficult to secure (Goodinge, 2000). This situation can be compounded because disabled parents commonly experience attitudes from professionals that are based on the assumption that impairment or illness in itself (inevitably) leads to child deprivation, potential harm or abuse (Morris, 2003). However, advocates for disabled parents have argued for an approach which recognises that risks are created and/or exacerbated by the lack of appropriate support, unequal access to mainstream services, the negative attitudes of practitioners, and the poverty and poor housing which can be associated with physical/sensory impairments and learning difficulties (Morris, 2003; Newman, 2003; Wates, 1997).

This set of difficulties is particularly likely to manifest itself during the community care assessment process. Disabled people are entitled to receive an assessment to judge their needs for community care services and, if they meet the local authority's eligibility criteria, to have those assessed needs met. They are also entitled to be offered 'direct payments' (an alternative to directly-provided community care, whereby the local authority can give a person assessed of needing a service the money, in order for them to employ their own staff). However, one study showed that many disabled parents felt that assessments were dominated by a focus on parental 'incapacity' instead of a focus on support that would enhance their ability to look after their children (Morris, 2003).

Newman (2003) argues that this problem-focused approach to practice is often reflected in the approaches adopted by researchers. Thus, disability research has tended to be preoccupied with identifying the negative impacts of parental disability on children, the identification of risk factors and the development of strategies for

protecting children. More recently, there has been a trend towards the involvement and participation of the public in general, and service users in particular, in research focused on issues that affect them (Oliver et al., 2004). The commissioning and control of research by service user groups has the potential to re-frame research aims and objectives in line with the priorities of members of those groups, rather than with the preoccupations of researchers and practitioners. It is within this context that the current research study was formulated, it being commissioned by the Disabled Parents Group at Cheshire Disabilities Federation (CDF). The standpoint of this study is neither that parental disability is always a source of risk or suffering for children, nor that it will leave children unaffected and not in need of help or protection. It is rather that parents are the most important source of support for children regardless of disability, and supporting them in their parental duties is the best way of safeguarding children's present and future welfare.

1.2 Aims and objectives of the study

This study takes as its starting point the view that differing levels of support may create the conditions within which it is difficult for disabled parents to carry out their parenting role in all its different dimensions. It explores the experiences of disabled parents in Cheshire in order to represent accurately disabled parents' perspectives on their experiences of using local services. The study therefore has the potential to inform local providers and advocacy groups about the strengths and weaknesses of local provision as well as provide them with an evidence base from which to work towards improving local provision. This study aims to elicit the views of a sample of disabled parents with specific reference to accessing and utilising the following:

- education (including early learning);
- health services;
- social services;
- childcare;
- housing adaptations and equipment;
- leisure activities;
- direct payments.

1.3 Study design and methods

Given that the research was commissioned by CDF it was guided by a steering group, the Disabled Parents Steering Group. All aspects of the research project were discussed and agreed with the Steering Group, particularly those aspects that related to the development of the research instrument – the questionnaire – and the

recruitment of research participants. In order to explore disabled parents' experiences the study used a series of in-depth telephone interviews with disabled parents.

1.4 Ethical approval

The study received ethical approval from the School of Applied and Health Sciences Research Ethics Committee at the University of Chester in May 2006.

1.5 Structure of the report

Chapter 2 provides a review of the literature on the experiences of disabled parents and locates this within the social model of disability. Chapter 3 describes the study design and methodology adopted and Chapter 4 presents the findings. The implications of the findings for policy and practice are discussed in Chapter 5.

Chapter 2

Literature review

2.1 Introduction

Debates about parenting with a disability can be profoundly emotive. The consequences for children, particularly those children who might be described as young carers, are often discussed within the context of a responsibility to protect children and not to burden them with 'adult' responsibilities. However, contemporary understandings of disability have been somewhat revolutionised during the past few decades, as the views of disabled people as users of services have emerged through the process of advocacy and research. This has led to the development in the literature of the idea of a 'social' model of disability. This Chapter briefly outlines the social model of disability and then goes on to examine and discuss what research has revealed about disabled parents' experiences of using services. This Chapter therefore provides an important context to the current study.

2.2 The social model of disability

The social model of disability is based on the view that the problems that disabled people experience are not a direct consequence of their impairment, be it sensory, physical or psychological, but rather the failure of public bodies to make the necessary environmental or attitudinal changes, and that these constitute the real barriers to their social inclusion (Newman, 2003). If parents become dependent due to illness or disability, then the needs generated might be met from either formal sources (such as adequately funded community care support) or informal sources, (such as friends, family or neighbours), such that the impact of any disability may be largely eliminated. This broadly summarises the main dimensions of the social model of disability, or social oppression theory as it is sometimes called (Oliver, 1998).

Terminology used to describe incapacities is inconsistent and there is a lack of consensus regarding the definition of disability (Newman, 2003). Different descriptions are used by legislators, academics, practitioners, members of the public, journalists and disabled people themselves. In 1980, the World Health Organisation (WHO) developed a classification system, the International Classification of Impairments, Disabilities and Handicaps (ICIDH). By *impairment*, the ICIDH meant the loss of a physical or psychological function, by *disability*, the inability to perform a commonplace activity as a result of impairment, and by *handicap*, the result of

disabilities being of sufficient magnitude to exclude a disabled person from the performance of a 'normal' social role (Newman, 2003).

The social model of disability locates the genesis of disablement in the social and physical environment and hence seeks solutions primarily grounded in social and political action. As a higher order concept, the social model bases its rationale on human rights. The model implied by the ICIDH, often described by its critics as a 'medical' model, views disability as primarily a personal problem, arising from trauma or ill health, which requires medical management and care by professionals. While the increased politicisation of the disability rights movement and the accompanying rhetoric has tended to polarise these models (Bury, 2000), there can be little doubt that the social model has been influential, not least in driving the revision of the ICIDH, re-named the International Classification of Functioning, Disability and Health (ICF). The ICF model, adopted by the WHO as an international standard to describe health and disability, explicitly moves from indicators based on mortality and morbidity, to indicators based on 'life', that is to say, what actions need to be taken to promote and prolong healthy life years (WHO, 2006).

Disability rights activists have used the social model of disability to propose that people are disabled by socio-political rather than personal factors, and, furthermore, to argue that the primary focus of intervention should be support for the parent, rather than support for the child. The dignity, rights, independence and self-esteem of disabled parents, it is alleged, are compromised by their portrayal as dependents, rather than citizens who are being failed by the state (Newman, 2003).

The social model of disability can be used not only to generate an understanding of the causes of problems but also to inform policy and practice responses to such issues. To illustrate this, it is instructive to look at the differing debates about how to solve the 'problem' of young carers. Morris (1997) suggests that investment should be directed towards adequate support for families rather than young carer projects. However, Crow (1996) argues that this objection carries some of the limitations of the social model of disability, particularly the proposition that impairment is *only* potentiated by oppressive structures and has no (or limited) reality in isolation of these structures. This debate has important implications for the direction of social care services. If, as has been widely argued (Levin, Kearney, & Rosen, 2000), parental disability (notably maternal mental illness) is a strong predictor of child protection registration, the pressure for an urgent response is likely to result in

interventions based on a pathology model of mental illness. Conversely, if the impacts of parental disability are exacerbated by structural inequalities and social oppression, then a disproportionate focus on child risk factors will further stigmatise and disable parents (Tanner, 2000). Both positions appear to have legitimate objections to the main propositions of the other. Disability may be too heterogeneous a term for all its associated issues to be resolved through social action, however well resourced or planned, but on the other hand families are much more likely to be able to care for their children adequately if they are appropriately supported. This dispute starkly illustrates the collision between a model of child welfare services based on children's rights, and a model that sees parents as the main vehicle for the enhancement and protection of children's health and well being.

2.3 Support for disabled parents

In her report, *The Right Support* (2003), Morris asserts that too often, the first contact that parents with learning disabilities have with health and social services is at a child protection case conference. However, Jackson has argued that what was needed was:

... an automatic process of assessment, not about the risks to the child in a child protection context but about what was needed to enable the child to stay with the parents. (Jackson, 1998, p. 218).

In her work on parents with learning disabilities, Craft (1993) highlighted how any problems with parenting were exacerbated by poverty, inadequate housing, harassment and anxiety about losing a child into care. Research on the experiences of children of parents with learning difficulties has also found that parenting competence was linked to the amount of support available from family and social networks rather than parents' impairment (Booth & Booth, 1997). Furthermore, in these circumstances, children who take on a caring role are more likely to be adversely affected, as Dearden and Becker (2000, p. 43) argue:

It is the absence of family-focused, positive and supportive interventions by professionals, often combined with inadequate income, which cause the negative outcomes associated with caring by children and young people.

Towards the end of the 1990s the views and experiences of disabled parents, as well as the support requirements of this group were beginning to emerge through research (see for example, Wates, 1997; Wates & Jade, 1999). There was also at this time a shift in some children's charities that had funded 'young carers' projects

towards an emphasis on supporting disabled adults in their parenting role, seeing this as the key to the welfare of their children (Olsen & Wates, 2003).

Despite the recent evidence that suggests something of a shift in attitudes towards accepting that disabled parents are as capable as any parents in adequately caring for their children if appropriately supported, existing evidence suggests that there is a very mixed picture in terms of the quality of support and ease of access to services. The Department of Health report, *A Jigsaw of Services* (Goodinge, 2000), identified gaps in services to support disabled parents, and reported poor co-ordination, time delays and limited appreciation of the need for services to support the whole family.

A task force set up in 2000 with the support of the *Joseph Rowntree Foundation* had as its core focus the identification of the barriers that prevent disabled parents in being properly supported in their role as a parent. They found evidence that disabled parents commonly face the assumption that any illness or impairment would inevitably result in child deprivation, potential harm or abuse (Morris, 2003). There was a tendency for social work practitioners to think of disabled parents as being in need of *care* rather than *assistance* and that, furthermore, this undermined disabled adults' role as parents. Disabled parents themselves were found to experience anxiety and stress as a result of the tendency of some social workers to question whether they could look after their children properly; as Morris (2003) points out, this can result in an inappropriate service response and the importance of challenging attitudes held by some social work practitioners was highlighted. These 'disabling attitudes' are not of course limited to social work practitioners but can be common amongst any practitioner who comes into professional contact with a disabled parent: for example, legal professionals were found to hold negative attitudes about disabled parents, which are common in society generally (Morris, 2003) and a survey carried out by *Mind* found that almost two out of five parents with mental health difficulties felt that their ability to look after their children was unfairly questioned (Read & Baker, 1996). Advocates of disabled parents have stressed that independence is not about doing everything for oneself, but having choice and control over the assistance required to go about one's daily life (Morris, 2003).

The task force also highlighted the continuing barriers to services such as health and education. For example, evidence was presented that suggested that in some hospitals the maternity ward was the only ward that did *not* have facilities for disabled people. One parent spoke of a 12-week course organised by health visitors, which

was held in a venue inaccessible to wheelchair users; another described finding it difficult to participate at a baby clinic because the changing tables were too high (Morris, 2003). Problems of access to health services for disabled people in the USA was recently reported by Kroll, Jones, Kahn and Neri (2006), who found a variety of what they termed structural-environmental (inaccessible facilities and examination equipment) and process barriers (a lack of knowledge, respect and skilled assistance). It is likely that being a disabled parent (rather than person) can sometimes make situations more difficult. However, the fact that examples of good practice were uncovered in some hospitals indicates that it is possible to improve access for disabled parents, if such an anticipatory model of care is put into place. For example, one hospital had identified a member of staff whose job it was to check that disabled parents' needs are planned for and met appropriately (Morris, 2003).

Disabled parents have also reported experiencing difficulties in fulfilling their role as a parent in the context of their children's education. This was not only in terms of physical access (ramps, lifts, parking spaces, dropped kerbs, and so on) but also accessible communication, such as asking parents in what format they would prefer school reports, whether they require Sign Language interpretation at meetings with teachers, telephoning parents whose low energy levels meant they could not come to meetings and so on (Morris, 2003).

A recent study highlighted the important role of staff in enabling disabled parents to access support. Tarleton, Ward & Howarth (2006) explored the issues faced by parents with learning difficulties with the workers who supported them. Respondents who took part in the study reported that some staff did not understand the impact of having learning difficulties on individual parents' lives and had fixed ideas about what should happen to the children of parents with learning difficulties, often wanting a 'concrete outcome' for children which removed all risk (including being placed away from the family). Tarleton, Ward & Howarth (2006) explain that a consequence of these workers' attitudes and behaviours was that parents became disengaged from services because they felt that staff had a negative view of them and wanted to take their children away. They also identified that referrals to support services were often too late to be of optimum use. This highlights how parents who could most benefit from timely support are sometimes least likely to get it.

One key issue identified by the task force was whether disabled parents can access the assistance they need without their parenting being called into question, or their

children being considered to be at risk. In order to access assistance under the Children Act, a child is required to be considered 'in need'. The task force (Morris, 2003) found that many parents felt that there was a stigma attached to this: there is an association with 'child protection'. Moreover, family support may be available when child protection procedures are initiated because a child is considered to be 'at risk', but support is withdrawn when the child is no longer considered 'at risk' (or when a child is removed from the parent's care). The task force recommended that eligibility for such support should not be related to identifying that children of disabled parents are at risk of harm, rather, that disabled parents need assistance in order to carry out parenting tasks, that this need is likely to be ongoing, and that the need is related to their experience of impairment and disabling barriers, not to their child being 'at risk' (Morris, 2003).

Adequate support for disabled parents is also important within the context of supporting young carers. Disabled parents report that, alongside their concern that they may be unable to protect young children from some physical risks, their children become independent at an earlier age than the children of non-disabled parents, and are thus better equipped to deal with hazards (Wates, 1997). Wates, (1997, p. 50) herself disabled, cites one of her own children describing the gains and losses that result from parental disability:

There are some places we can't go without you, but when we go to a theme park we don't have to queue up for the rides. It's a pity you can't play the running games but we like it when you can't catch us when we've been naughty! It's horrible when you fall over but it's fun playing with the scooter. Wherever we go you need help and so we're always meeting friendly people.

A body of evidence exists which provides some support for the proposition that the additional responsibilities involved in situations where children are having to deal with adversities may, in many circumstances, be a positive factor in a child's development. It is suggested that more cohesive parent-child relationships may develop, and the accomplishment of tasks important to the household economy may result in enhanced self-esteem for children (Glass, 1985; Greer, 1985; Blackford, 1999). Although disabled parents themselves show a clear consciousness of the dangers of making excessive demands on children, they show no sign of abdicating their role as parents, as the following quotation from a disabled parent illustrates:

It's really easy to get Melissa to do things for me. She will do things I can't do. She'll go to get a tool, or I hold her up to get things I can't reach. But disabled parents have to be careful.

We have to let our sons and daughters be children and do the things they want. They have their own little minds and their own priorities. We can't let them become robots for our sake. (Brown, 1981, cited in Newman, 2003, p. 33).

Overall, the research literature reveals a very patchy picture with regard to the ease with which disabled parents can negotiate access to support services. Kroll et al. (2006) explain the problems that disabled people face in terms of a blend of structural-environmental factors (such as access to buildings) as well as process factors (such as the knowledge, attitudes, skills and predispositions of practitioners with whom disabled people come into contact). One relatively recent policy development has been the introduction of direct payments, which has the potential to empower disabled parents in terms of choice and control of the support they receive.

2.4 Direct Payments

Direct Payments are made by social services departments, who can make cash payments in lieu of services to meet assessed need (under either community care legislation or the Children Act), and by the Independent Living Fund (ILF) (Morris, 2003).

Since the publication of *Fair Access to Care Services* (FACS) guidance, social services should be considering 'family roles and responsibilities' when carrying out community care assessments (Cestari, Munroe, Evans, Smith, & Huxley, 2006). However, the task force (Morris, 2003) was informed by the Director of Research at the ILF that the ILF's Trust Deed specifies that ILF grants can only be used to meet assessed needs for personal care and domestic assistance and not for child care or support needs related to parenting a child. While there may be ways of combining direct payments from a social services department with ILF grants in ways which meet parents' holistic needs, the task force viewed this as an unfortunate limitation on the support that could be funded through ILF grants. It also views it as at odds with the inclusion, within FACS eligibility criteria, of 'family roles and responsibilities'.

A number of concerns were raised by the task force members about direct payments (Morris, 2003). They welcomed the commitment, within the Health and Social Care Act 2001, to require local authorities to make direct payments available to those who qualify. However, take-up of direct payments remains low (Morris, 2003), and there are wide variations in the practice of social workers and managers in terms of opening up the possibility of direct payments to disabled parents. Task force

members argued that there is a need to build knowledge and understanding about how direct payments could make a real difference.

2.6 Conclusion

The literature presented in this Chapter has illustrated that the last few decades have seen some significant changes in thinking about disability. The social model of disability places emphasis on structural and environmental factors in explaining the causes of unequal provision of services and access to services for disabled parents. This view is juxtaposed with a model that sees disability as primarily a personal problem, which requires a system of care that protects children from harm. These two polarised views are key to informing how the issues that surround disabled adults as parents are dealt with by services and individual professionals. Whilst there is some evidence to suggest that progress has been made in recognising the rights of disabled people to be parents, evidence suggests that both support services and community care services still fail to address adequately the needs of many disabled parents. This study set out to explore the extent to which this was evident at a local level.

Chapter 3

Study design and methods

3.1 Introduction

This Chapter outlines the methodology used in the study, as well as explaining the ways in which the researchers worked with the commissioning organisation. It also explains the changes that were made to the original proposal for a large quantitative survey and why a smaller scale, more in-depth qualitative piece of work was carried out. The research project was overseen by the Disabled Parents Steering Group at Cheshire Disabilities Federation, the members of which had identified the original idea for the research and secured some funding from Cheshire Children's Fund to carry it out. The Centre for Public Health Research (CPHR) at the University of Chester was commissioned to help them take their idea for the research project forward.

3.2 Study design

Discussions took place between researchers from the CPHR and the Disabled Parents Group, together with the Programme Manager from Cheshire Children's Fund, to scope the research project and define the methodology. The intention was to conduct a telephone survey of disabled parents in Cheshire that would allow some quantification of problems and issues and some analysis by sub-groups. In order to ensure that efficient use was made of the available resources, telephone interviews (with the exception of those participants recruited via the Deafness Support Network – see below) were to be used, based on a structured questionnaire that comprised open and closed questions. However, early on in the project it became evident that generating a sufficiently large sample of research participants was going to be problematic. Thus, a decision was made to embark on a predominantly qualitative, approach to the telephone interviews. This meant that a smaller number of participants could be recruited and that their experiences would be explored in depth.

3.3 Participants who took part in the study: sampling strategy

The aim of the study was to gather the views of as many disabled parents as possible. The eligible population was all disabled parents with at least one child under 16 years of age living in Cheshire. The exclusions to this were those parents with a severe learning disability or severe mental illness.

Recruitment of research participants to the study took place through three different organisations: CDF, Cheshire Social Services (via the direct payments project manager), and the Deafness Support Network. Participants were recruited during a six month period (July – December 2006) to allow as many participants as possible to take part in the study.

In order to protect participant confidentiality members from two of the participating organisations (CDF and Cheshire Social Services) sent out a letter of invitation to disabled parents with whom they were in contact and who met the inclusion criteria (Appendix 1). Included with the letter was a participant information sheet (Appendix 2) to provide further, more detailed information about the study. There was a tear off 'consent to be contacted slip' on the participant information sheet and individuals willing to participate in the research were asked to fill in their contact details and return the slip in a pre-paid envelope to the CPHR. Alternatively, participants were able to contact the researcher by telephone, or email to register their interest in taking part in the study. Participants were then contacted by the researcher to arrange a convenient time for the telephone interview to take place.

Participants were also recruited via the Deafness Support Network using the same process. Participants who agreed to take part were given the telephone interview schedule in questionnaire format (Appendix 3) and asked to complete it as fully as possible. Two participants were recruited via the Deafness Support Network. In total, 16 disabled parents participated in a telephone interview.

3.4 The telephone interviews

The telephone interviews were carried out using a questionnaire (Appendix 4), which was developed in collaboration with the Disabled Parents Steering Group as well as being informed by current literature on the issues that disabled parents have experienced. An initial draft of the questionnaire was produced that was sent to the direct payments project manager for Cheshire Social Services and Cheshire Children's Fund for comment. A second meeting with the Disabled Parent Steering Group and the Cheshire Children's Fund Programme Manager was held to discuss comments and finalise the questionnaire.

The aim of the questionnaire was to enable disabled parents to describe their experiences of using local services, including the quality of their interactions with staff. It took the form of a structured questionnaire that contained both closed and

open questions. In terms of the former, a series of questions were asked that had a standard set of responses (for example, strongly agree through to strongly disagree). In terms of the latter, open ended questions were asked that allowed parents to develop their own response unimpeded by specified response categories. This enabled them to identify and express those issues and events that were of significance and importance to them in terms of describing their experiences.

The questionnaire was piloted with five disabled parents. Feedback from the piloting indicated that the questionnaire took a long time to complete. The length of the questionnaire was not altered however, as it was decided that it was important to try to elicit comments on all of the different domains of parenting. The telephone interviews each took between 30 minutes and two hours and 30 minutes to complete, the longer ones being conducted in two separate sessions.

3.5 Data analysis

The responses to the closed questions were entered onto an SPSS database and analysed using this software. Descriptive statistics were used to analyse the data. Open-ended questions were analysed through a process of developing themes from the narratives.

Chapter 4

Findings

4.1 Introduction

This Chapter presents the findings from the telephone interviews. It begins with a brief overview of the sample in order to provide some context to the findings themselves. The qualitative and quantitative data are organised under the following headings: school and early learning; childcare; transport; health services; social services; direct payments; housing adaptations and equipment; leisure and other activities; general comments. The quantitative and qualitative data have been combined under each of these headings in order to present a coherent description of parents' views of their experiences.

Parents in the study were asked to respond to a number of closed questions regarding their experiences of being a disabled parent. As explained earlier, the original idea in devising these questions was to enable some quantitative analysis of the sample based on comparisons between parents according to different variables. However, this required an adequate sample size. In reality the problems encountered with recruitment of disabled parents to the study meant that any meaningful quantitative analysis of the data was limited because of the small numbers in individual categories. However, the following presentation of data can be used to give some indication of the views of disabled parents on their particular experiences. This quantitative data is complemented by the qualitative data, which has been used to explore parents' experiences in more depth. A number of themes were identified in parents' qualitative narratives, which are discussed in detail below. Illustrative quotations from the interviews are used throughout, which have been anonymised and are referred to by code only.

It is worth noting at this juncture that the main purpose of the research was to explore disabled parents' views of their experiences of using a variety of health, education and social care services and to use their narratives to identify what was important to them. It is evident from the analysis that being a disabled *person*, regardless of whether or not the person was a parent, was often the source of a variety of problems. However, in addition to this, parents described a variety of experiences and consequences that were the combined result of being *disabled* and being a *parent*. Thus, it was evident from the qualitative data that being a *disabled parent* can

add a layer of complexity to parenting. Although not explored in detail in this study, it is likely that the particular experience of parenting as a disabled parent is also influenced by the particular nature of the disability as well as other factors to do with family structure – such as being a single parent – and other socio-demographic factors – such as parenting in poverty.

The aim of this Chapter is to provide a description of disabled parents' experiences. In so doing, the analysis has sought to capture the similarities as well as the differences in parents' expressed views.

4.2 The sample

A total of 16 parents took part in the study, and of these two were male and 14 were female. Their ages ranged from 25 to 54 years of age (three were aged 25-34 years, eight parents were 35-44, four were 45-54, and one person did not disclose his/her age). Ten parents were married or living with a partner and six were single parents. All children lived with their parents, with the exception of one who was partly cared for by someone else. In terms of parenting responsibilities:

- six parents had one child;
- six had two children;
- three had three children; and,
- one parent had 4 or more children.

Of those who took part in the study:

- 44% (7) stated that they had had some form of contact with children's social services while 56% (9) stated that they had not;
- 56% (9) were receiving help with their responsibilities as a parent while 38% (6) were not. One participant was 'not sure'.

The study actively sought to include parents with different disabilities. The parents who took part in the study had the following disabilities:

- myasthenia gravis;
- Friedrich's ataxia;
- muscular dystrophy;
- multiple sclerosis;
- rheumatoid arthritis;
- osteoarthritis;
- retinitis pigmentosa;

- spina bifida;
- profound deafness.

Some parents had more than one disability.

4.3 Parents' experience of school and early learning

Table 4.3.1 shows parents' ratings of their experiences of being able to take part in their child, or children's education. Three parents said that this question was not applicable. Of the remaining 13 parents who answered the question, there was some variation evident, with just under two thirds (62%, 8 parents) rating their experience positively. However, whilst no parent rated their experience as very negative, a minority of parents rated their experience as either satisfactory or negative (38%, 5 parents).

Table 4.3.1 Parents' experience of taking part in their children's education

	n	%
Very positive	4	31
Positive	4	31
Satisfactory	2	15
Negative	3	23
Very negative	0	0
Total	13	100

Table 4.3.2 shows how parents rated their relationship with the school that their child or children attended. Of the 14 parents for whom the question was applicable, most parents rated their relationship as good or very good (72%, 10). However, again a small minority of parents responded that the relationship was satisfactory, poor or very poor (28%, 4).

Table 4.3.2 Parents' description of their relationship with the school and staff at the school

	n	%
Very good	4	29
Good	6	43
Satisfactory	2	14
Poor	1	7
Very poor	1	7
Total	14	100

Table 4.3.3 shows whether or not parents thought they were able to take part in school activities. Whilst parents responded differently to this question, it is evident

that over half the respondents (56%, 9) thought that they could not participate in school activities.

Table 4.3.3 Whether or not parents were able to take part in school activities

	n	%
Yes	4	25
No	9	56
Not sure	3	19
Total	16	100

Due to the variety of disabilities and also the different personal circumstances and family structures of parents who took part in the study, their experiences of school and early learning were varied and contrasting. However, the responses to the open ended questions gave some insight into why parents were not able to participate in school activities. Parents talked about access to the school and its facilities as well as the degree of support that it offered to disabled parents in terms of trying to accommodate and encourage them to participate in their child's education. It is likely that these two factors influence the kind of relationship that parents are able to develop with the teachers.

Some parents reported access to the school as being very good and that they felt well catered for. For example, some parents reported that the school had been prepared to accommodate them by making changes where possible. In one case, the school had been particularly helpful in overcoming practical difficulties. For example, one parent said:

'... they even moved the classroom around for me to make it easier for me to get around, so that's a good positive thing.'
(P7).

A number of parents also reported that where practical problems were encountered that were difficult for the organisation to change, staff had been forthcoming with offering help or alternative solutions. One participant gave the following example:

'The only real thing with the nursery is that because I'm in a wheelchair, the nursery isn't accessible at all. It's difficult for me to go ... it's an old building with lots of steps ... the staff are really good, they don't mind speaking to me on the phone as they know that I can't call in.' (P2).

Other parents however, reported that access had been poor and explained that they had not been satisfied with the school's ability to accommodate disabled parents. For example, one parent made the following comment:

'It was very awkward, I had to apply to get special treatment, I mean, to get all the teachers to come to me instead of going all round to them and it wasn't nice really. They did try for the first couple of years but towards the end of it I just didn't go at all, I just sent my husband because it just wasn't disabled friendly at all, and then I missed out, which wasn't really acceptable.' (P13).

In this particular case the parent went on to describe how, as a result of restricted access, she felt it had damaged her relationship with the school. She commented:

'My relationship with the staff suffered a lot. I didn't have any real feedback from them at all. I don't know whether any of them knew he [son] had a disabled mum or just thought I didn't exist.' (P13).

A number of parents talked about the lack of appropriate parking facilities in schools. Parents said that there was a lack of understanding on the part of schools about providing parking that was both adequately sized and in close proximity to the main entrance of the school. One parent explained how she had decided to enlist the help of social services in order to persuade the school to allow her to park within the grounds of the school. She explained:

'I had to get my social worker to ring up the school and press them, diplomatically, to allow me to park in the school because of the blue badge thing; when it was very bad weather it was hard for me to stand. And she had to ring up because I couldn't get them to understand that. But I wasn't able to get that sorted until my social worker rang on my behalf so I had to use social services.' (P11).

Parents also talked about the support the school offered them and the encouragement they received to participate in the life of the school wherever possible. It was evident that this was important to parents, as the following quotation illustrates:

'They encourage me to come in and help out. When I first went there they said "we'd love you to come again" and that sort of thing, which really helps.' (P7).

Many parents also praised individual members of school staff for helping and being as supportive as they could be. However, some parents expressed the view that they had to accept that they would not be able to take part as much as other parents by virtue of their disability. Alongside these positive comments, a number of parents

reported feeling unsupported by the school, with little if any encouragement to participate in activities. One parent reported being denied access to speak to the head teacher to discuss issues to do with disability. Another parent who was visually impaired gave the following illustration of the lack of support:

'I've never had any support from the school ... they send me stuff in normal print ... they don't cater for anything.' (P8).

4.4 Parents' experience of childcare

Table 4.4.1 shows parents' ratings of ease of access to childcare. This question was not applicable to four parents as they were accessing childcare through members of their immediate or extended family. Of the remaining 12 parents, no-one said that it was 'very easy' to access childcare, compared with 33% (4 parents) who said that it was extremely difficult. A further 42% (5 parents) said that it was either OK or difficult.

Table 4.4.1 Parents' ratings of being able to access childcare

	n	%
Very easy	0	0
Easy	3	25
It is OK	3	25
Difficult	2	17
Extremely difficult	4	33
Total	12	100

Table 4.4.2 shows parents' ratings of being able to find affordable childcare. (Again, this question was not applicable to four parents as they were accessing childcare through members of their immediate or extended family.) No parents said that it was easy or very easy. The data show that accessing affordable childcare is either difficult or extremely difficult for 84% of parents (10).

Table 4.4.2 Parents' ratings of being able to find affordable childcare

	n	%
Very easy	0	0
Easy	0	0
It is ok	2	16
Difficult	5	42
Extremely difficult	5	42
Total	12	100

Table 4.4.3 shows parents' views on whether or not they felt they would be more able to take part in community activities if adequate childcare was provided. For 50% of parents (8) it was thought that this would make a difference to being more able to take part in community activities.

Table 4.4.3 If adequate childcare was provided would parents feel more able to take part in community activities?

	n	%
Yes	8	50
Not sure	6	38
No	2	13
Total	16	100

The qualitative comments of parents shed further light on their experiences of accessing childcare. While many parents said that information about how to access childcare was scarce, and that childcare services were expensive, individual experiences of using and accessing childcare were different depending on how parents accessed childcare. Those who were accessing childcare through social services made more negative comments about the childcare compared to those who were using direct payments to fund childcare services.

Parents using childcare services through social services specifically commented that they were inflexible and did not cater fully for their needs. For example, one parent commented that she was not able to access services for her daughter as she was not classified as being disabled. She said:

'I cannot get anyone in the home who is prepared to help both me and my daughter; they won't touch my daughter because she isn't the one who is disabled.' (P1).

In contrast to this, parents accessing childcare services through direct payments commented that they were able to use them flexibly to fit in with their daily lives, rather than having to structure their lives around the times that services were available. As an example of this, one participant made the following comment:

'I get direct payments which I use some of for my childminder to take [daughter] to school and back which I can do now, which is great.' (P7).

These comments illustrate the degree of choice and flexibility that direct payments gave disabled parents.

4.5 Parents' experience of transport

Table 4.5.1 shows how easy parents thought it was to get around with their children. One parent said that this was not applicable as they were not able to leave their home due to their disability. The responses from parents varied, with the majority (66%, 10) indicating that it was extremely easy, easy or OK. However, for a minority of parents (33%, 5) getting around was difficult or extremely difficult.

Table 4.5.1 How easy parents thought it was to get around with their child or children

	n	%
Extremely easy	2	13
Easy	2	13
It is ok	6	40
Difficult	3	20
Extremely difficult	2	13
Total	15	100

The reasons why some parents found it difficult to get around with their children are likely to be complex and influenced by a variety of factors: the nature of the disability; access to private transport; ages of children; access to informal help; and so on. Almost all of those who took part in this study explained that they seldom, if ever, used public transport to get around with their children. Parents described how it was especially difficult to use rail travel due to the height of the step up to board a train. Parents also reported a lack of ramps, and where ramps were available, there was often a lack of appropriately trained staff to assist them. Regarding rail travel, one parent said:

'It was appalling – steps up for one, I don't know how they expect you to get yourself on board , let alone your child with a buggy and so on.' (P11).

The bus service was perceived by parents as being marginally easier to use than rail travel. However, some parents said that the poor reliability of the service discouraged them from using it. One parent commented:

'We sometimes use the bus; it's ok when the buses come. We have one bus every twenty minutes when it comes but it's a bit hit and miss.' (P8).

It was also evident that for those parents whose children were older, public transport was less of a problem because their children were more independent themselves as well as being able to assist their parent, as the following comment illustrates:

'Now the children are older it's easier, they can actually help me get on and help me find a seat and what not.' (P8).

The problems experienced with public transport meant that a number of parents used their own cars to transport themselves with their children. However, this was not without its own difficulties. Parents who used their own cars described how they were limited in terms of the places they could go. While parents said that using their own car was beneficial in terms of the space it afforded them to take equipment with them, a number of parents described how they would often need assistance once they arrived at their destination, and, as a result, were discouraged from making some journeys with their children. Again, this was dependent on the particular circumstances of parental disability, the age of children and the specific venue. One parent described her experiences thus:

'It's very easy taking [daughter] to school in the car because I can park in the disabled parking bay at the school and park at my home, so it's very easy to get her into school and into home again. But if I was going to somewhere like a shopping centre, then it would be a different story.' (P7).

This quotation is a good illustration of the difference that changes to the environment can make in terms of enabling the independence of disabled parents in their everyday lives.

4.6 Parents' experience of health services

Table 4.6.1 shows how parents described their relationship with their GP. Again responses varied across all categories. However, overall, the majority (57%, 9) of parents rated their relationship with their GP as either very good or good. However, for a minority of parents, the relationship was either poor or very poor (24%, 4). Given the important role the GP has in the lives of many disabled parents, this is worthy of note.

Table 4.6.1 Parents' description of their relationship with their GP

	n	%
Very good	7	44
Good	2	13
Satisfactory	3	19
Poor	2	13
Very poor	2	13
Total	16	100

Table 4.6.2 shows parents' experiences of attending hospital as an outpatient. (This question was not applicable for one parent.) For the majority of parents, their experience was rated as at least satisfactory (73%, 11). However, again, a small number of parents (27%, 4) described their experiences of attending hospital as very poor.

Table 4.6.2 Parents' experience of attending hospital as an outpatient

	n	%
Very good	1	7
Good	3	20
Satisfactory	7	47
Poor	0	0
Very poor	4	27
Total	15	100

Table 4.6.3 shows parents' description of the relationship they had, or have currently, with their health visitor (the question was not applicable for two parents). The data shows that over half the sample (57%, 8 parents) indicated that they had a very good relationship with their health visitor. However, 42% of parents (6) indicated that this was satisfactory or worse

Table 4.6.3 Parents' description of the relationship they had (or have) with their health visitor

	n	%
Very good	8	57
Good	0	0
Satisfactory	3	21
Poor	1	7
Very poor	2	14
Total	14	100

Table 4.6.4 shows parents' description of the relationship they had, or have currently, with their midwife. (The question was not applicable for five parents.) The majority of parents (63%, 7) described their relationship as either good or very good. Again however, this contrasted with a small number of parents for whom their relationship was poor or very poor (18%, 2).

Table 4.6.4 Parents' description of the relationship they had (or have) with their midwife

	n	%
Very good	4	36
Good	3	27
Satisfactory	2	18
Poor	1	9
Very poor	1	9
Total	11	100

Table 4.6.5 shows how parents rated their experience of attending antenatal classes. Six parents said that this question was not applicable to them because they did not attend antenatal classes. They said that this was because they knew that they would give birth via caesarean section and therefore were not required to attend. However, given that antenatal classes are designed to cover a number of aspects of pregnancy, birth and caring for a newborn baby, disabled parents appear to have been excluded from classes from which they may well have benefited. Of the remaining 10 parents 90% rated the experience as good or very good.

Table 4.6.5 Parents' experience of taking part in antenatal classes

	n	%
Very good	2	20
Good	7	70
Satisfactory	0	0
Poor	1	10
Very poor	0	0
Total	10	100

The data above show that parents' experiences of using and accessing health services was mixed and this was also evident in the qualitative narratives where both positive and negative comments were made across a range of different health services. Parents' comments could be grouped in relation to three themes: support and facilities; expectations of disabled parents; and, consistency of care. It was evident from the narratives that many issues related to the issue of being disabled, regardless of whether or not the person was a parent. However, parents articulated the view that many issues were exacerbated when it came to taking children to different NHS facilities.

Parents reported experiencing difficulties in relation to facilities for disabled people in both GP surgeries and hospitals and in this respect this was no different from the

kinds of comments that were made about accessing and using schools and child care buildings and facilities. One parent noted that there were no disabled toilet facilities in the GP surgery she was registered with. This created a difficulty when she took her children to see the GP, if a urine sample was required. She stated that:

'There's no toilet in the practice that I can access which makes it difficult if you've got a child who's ill or has to give a urine sample or something like that. You have to go home and do it and come back, which is a hassle.' (P14).

The same parent also commented that the surgery itself was not disabled friendly and made the following statement:

'The way that it's set out isn't very good, even though it's a new building but it's very difficult to get in and out. When you go in to speak to the receptionist the level of the desk is at chest height for a standing person which for me is above my head. And there are no disabled parking spaces.' (P14).

Parents also reported a lack of facilities for disabled people in hospitals – toilets and parking spaces for example – which, they explained, made it more difficult for them to provide care and support to their children when they were receiving hospital treatment. For example, one parent said:

'My son had to go back into hospital but while he was there I couldn't stay with him to feed him because they had no disabled facilities in the hospital. I couldn't use their rooms and I couldn't believe it!' (P11).

A number of parents also described how, in their experience, the level of care and treatment was poor. Whilst these kinds of situations may well be experienced by non-disabled people, there may also be additional factors associated with the level of care and treatment that are related to the hospital's capability to provide appropriate facilities, care and treatment. Some of this may be to do with providing appropriate facilities but care and treatment may also be a reflection of staff attitudes towards patients with disabilities, including those who are disabled parents. One parent described her experience of hospital treatment thus:

'The wards and the room were filthy and the consultant was really unhelpful. I was treated very badly and I ended up having to have an emergency caesarean and treated badly after that, an awful lot of physical problems and it was after that that I developed rheumatoid arthritis. The after care was pretty shocking.' (P5).

For some parents, poor treatment and care continued after they had given birth, with staff showing a lack of understanding about how they might need to adapt their

practice in order to help disabled parents make the transition to parenting a new baby. One parent described her experience as follows:

'There was no understanding whatsoever, no help given. Even to do the easiest things like feeding the baby, I had to get someone and ask them "how am I supposed to get the bottle in the baby's mouth?" Because I couldn't see. And basically they didn't really have a clue.' (P8).

Some parents also said that they felt unsupported and when they asked for help they were left to cope on their own. In explaining the help that she had tried to get from her health visitor, one parent said:

'She wasn't very good because you'd ring her up and she wouldn't come out and see you; she just said "don't bother me". It was just sort of, you've got to cope on your own.' (P12).

In contrast to these comments, a number of parents reported positive experiences in respect of the support available to them after pregnancy. Describing her experience of support from the health visitor, one parent explained that she had tried to accommodate her. She said:

'The health visitor was very good and very supportive. I wasn't able to go to baby clinics so she always came over and lugged her scales through the door so she could weigh [daughter] for me and she did the three months checks and other checks at home. But also I still see her because of my rheumatoid arthritis, and she's helped me with the benefits that I'm entitled to so I can't fault them there.' (P5).

A number of parents also reported positive experiences with regard to accessing and gaining support from their GP surgery. One parent described how she was given '*special treatment*' to accommodate the fact that she was a disabled parent and therefore had different needs and difficulties that would not be encountered by a non-disabled parent, as the following quotation illustrates:

'Once or twice when I've gone to the doctors, they have realised that it's not that easy for me to get there, and they've said to me that if her symptoms persist, they've given me a swab so I could just get the health visitor to call round and they can take it for me. So they've kind of let me off the hook really as with a normal person they'd say 'oh come back in a week' but with me they realise that it's not that easy for me.' (P2).

A number of parents also described how they had felt supported prior to giving birth and how they appreciated the fact that their disability was recognised by health professionals with whom they came into contact. This meant that they were not

excluded from taking part in activities, but instead some amendments were made to accommodate them. In relation to attending antenatal classes one parent made the following comment:

'I had a very good experience; they were very helpful and informative. They would take account of my disability, she [the midwife] would say to the other ladies "you all do this" and then she would tell me to do something else. So I was told the best way for me to cope with labour and I did cope with it and I was able to have a natural labour.' (P13).

A number of parents expressed the view that some health professionals took a negative view of the fact that they were going to be a parent when they had a disability. Some parents explained that because they were disabled, there was an assumption or expectation by some health professionals that they should not become a parent. Explaining this, one parent made the following comment:

'I did actually see a couple of different midwives who were quite patronising and quite negative and the first question they asked me when they walked in was "how are you going to cope with a baby?"' (P7).

Some parents described how some health professionals appeared to be reluctant to accept the idea of them becoming a parent, and, furthermore, did not express any empathy towards them in terms of the challenges that they would face as a disabled parent. One parent explained this thus:

'I was astonished that the midwives more or less told me off for having any children; they treated you like you were a school girl of about 12! I was also told off for crying as well. They said "you shouldn't be crying, you've just had a baby". They just didn't have any idea; I'd been in intensive care, damn near died again, I had to learn to walk again and they just had no idea at all what I'd been through.' (P11).

A number of parents also described how, in some cases, the attitude of those health professionals who showed concern that disabled parents would not be able to properly care for their children led to parents feeling under pressure and scrutinised. One parent for example said that this was a constant pressure and that she would do as much as possible so that she could not be accused of being an unfit parent, as the following quotation illustrates:

'That is a worry all the time, and it is always in the back of your mind, are they watching me to see if I'm a good mum and that I can manage?' (P7).

Some parents also expressed the view that some health professionals at the hospital were uncaring, and showed little interest in them as mothers, or in the child's well-being. In one case, a parent who had broken her arm and was taken into hospital described how she was treated. The following quotation illustrates the way in which her disability itself presented difficulties for staff, as well as the consequences of her accident for her parenting capacity on discharge:

'When I broke my arm and had to go into hospital they didn't take into consideration my osteoarthritis or anything about it. I remember when I was half passing out and screaming at them – don't lie me on my right hip I've got arthritis – and they were just ignoring me, because they just didn't believe me. I went in and I had these splints on my wrists and I have these little gloves that I wear on my hands to keep the swelling down, and they were saying "what on earth are these? What are these for? Can we cut them off?" They didn't even know what they were. Nobody said "oh, we'll get in touch with your GP" and when it came to me going home none of the nurses asked me, they knew I was a single mum, "how are you going to manage with your children, do you want me to get your social worker for you", I had to ask. And then the nurses on the front desk said "oh well it's the weekend so the social workers aren't there, you'll just have to go home".' (P6).

In contrast to these experiences a number of parents reported experiencing services that were responsive and which were able to meet their needs. For example, one participant made the following observation about her experiences of giving birth in hospital:

'All the staff at the hospital were fantastic with me. And there were no prejudices there because I was disabled or anything like that.' (P12).

Another theme that emerged from discussing health services with parents was the importance of consistency of care such that they could become familiar with health professionals and develop some kind of relationship. Many of those who took part in the study explained that they felt reassured by dealing with a health professional that was familiar with them and their family circumstances, and, in some cases, quite rare conditions. Many described feeling frustrated when dealing with a 'new' health professional who was not aware of the exact circumstances they were in, or the details of their disability. For example, one parent described how she was unable to be prescribed the correct drugs by anyone other than her GP; she made the following comment:

'My GP is fantastic because she really listens, but when I can't get to see her and have to see other GPs they just haven't got a clue. For example, recently I've been told I could

have a certain pain killer and me and my GP had worked it out between us; it works really well but because it's unusual, if I see another GP they won't prescribe it for me and I have to wait to see her so there's been times when I've gone without medication, because they've been unsure, but this is in the same practice.' (P6).

4.7 Parents' experience of social services

Of those who took part in the study, 81% (13) had had a community care assessment while 19% (3) had not. Of those parents who had experienced a community care assessment, 62% (8) said that their parenting needs were taken into account during the assessment, 31% (4) said they were not, and 8% (1) were not sure. Further to this, 77% (10) of parents who had experienced a community care assessment stated that they were offered direct payments during the assessment, while 15% (2) stated that they were not, and one parent (8%) was not sure.

Of the 16 parents, 9 (56%) said that they were using direct payments. Those parents not using direct payments (44%, 7) gave a number of reasons for this, which are illustrated in Table 4.7.1. Under the 'other' category, two parents said that '*being on direct payments required taking on too much responsibility*' and '*I can't find anyone who will do it*'. Taken together the reasons given reveal a mixture of factors that are connected with ensuring that disabled parents are informed about direct payments as well as a number of concerns about the extent to which direct payments might involve additional responsibilities which parents were not sure they wanted to take on.

Table 4.7.1 Reasons given by parents who were not using direct payments

	n	%
I don't know about them	1	14
I don't want to use them	2	29
I was told that I couldn't have them	2	29
Other	2	29
Total	7	100

Direct payments, and the ways in which they were used to provide support, were explored in some detail with parents. All parents expressed the view that they felt empowered by being able to choose their support services. They also said that they felt it increased their independence, that it gave them more control over their daily lives and, furthermore, that this was important to them. The following quotation illustrates these views:

'I'd say direct payments has helped us a great deal. It means we can basically live as a family without having to rely on ... you see there was a suggestion that we would have to send our son away to nursery to reduce the care burden on social services but we found, well, because we stuck to our guns we got the care we actually needed; it means we can live as a family unit and do what most families do.' (P4).

However, a number of parents expressed the view that there was not sufficient help and support setting up and utilising direct payments. They likened using direct payments to running a small business, and, as such, it required skills in managing a budget, time, and people, skills which some parents said they did not have. Some of the parents who were not accessing direct payments cited this as the main reason for not doing so. Describing this aspect of using direct payments, one parent said:

'With DP you don't tend to get a lot of support say with staffing issues; you feel a bit on your own once it's set up. They do give you information at the start. It's just kind of dealing with people and having to manage staff, it's a new skill and I feel you're kind of thrown in at the deep end a bit. I think there should be more support for the use of DP.' (P7).

The interviews also explored other aspects of parents' relationships with social services and two main themes were identified from their narratives: the process of getting support from social services and fear of social services.

Parents' experiences of gaining support from social services were somewhat diverse and a number of different issues were raised. Many parents expressed the view that there was an unnecessary and unhelpful divide between adult and children's services. According to parents, this served to confuse them as to which services they could and should access to gain support. Some parents also commented that when they did contact social services, although they and their children were assessed, there seemed to be little consideration given to the parenting aspects of support reflected in the relationship that existed between parent and child. In relation to this one parent made the following comment:

'There was one assessment for me and a separate one for [daughter]. But there was no accounting for our relationship as mother and daughter; we were two separate entities.' (P1).

As well as creating some confusion, the divide between adult and children's services was also perceived by parents to lead to inter-departmental disagreement regarding the source of funding for support. Parents explained that they found this unhelpful in terms of creating a clear and easy way of gaining support. A consequence of this

was that the uncertainty became a source of stress and worry when what was needed was reassurance. For example, one parent said:

'We're always fighting against budgets and fights between both the adult social services team and the children's services team about where the funding comes from and I'd say it's been quite stressful at times to try and get everyone on our side to get the care package we need.' (P4).

A number of parents also described how they felt that social services were working against them rather than for them in terms of trying to secure the support that they needed to enable them to fulfil their parenting role and responsibilities. Furthermore, the processing of applications and general paper work did not happen quickly enough. Many parents explained that while applications were being dealt with, they were in need of care and support. According to parents this contributed to a growing lack of confidence in social services to be able to provide support. As one parent put it:

'The very people who are supposed to help me ended up being the very people that I am fighting, and this is a constant battle. I feel like I cried out for help but it's just not been there.' (P1).

A number of parents also explained that they found it difficult to find the information they needed regarding the kind of support or benefits they were entitled to. Fourteen parents, for example, said that they would like more information about direct payments. When asked whether they knew that direct payments could be used to support them in their parenting role eight parents (53%) said that they did not. One parent did not answer this question. One parent said:

'I feel it's very difficult to find out what you're eligible for, I found it very hard finding out what my rights were and how much pressure I could put on them to deal with my rights, and it's only now that I've been receiving care for quite a while that I'm more aware of the full extent of what I can ask for and what I'm entitled to. It's very difficult to get the information with regards to care when you're disabled with a child.' (P4).

Those parents who had been through the community care assessment process expressed the view that their children were taken into consideration during this assessment. In some cases parents had requested the presence of a representative from both adult and children's social services to enable them to create a support package that was appropriate for both them and their children. One parent said the following:

'Yes, the children were taken into account during the care assessment, they're actually named on the care sheet. They've taken into account that I'm a carer for them but also that they have to help me. That's written on the care plan.' (P6).

A number of parents also made positive comments regarding their experience of social services. Some parents described how social services had been helpful and efficient and they were appreciative of the support they were able to get. One parent said:

'I contacted children's social services myself and said "look, this is the situation can you help?" ... I think all the services were good, like I said, we all sat together to work out a care plan and I think funding is split half and half.' (P9).

A number of parents explained that they were reluctant to contact social services (particularly children's services) as they were afraid that they would come under scrutiny regarding their ability to carry out their role as a parent. Furthermore, parents expressed concern that social services might become involved in removing their children and placing them into care. This made some parents reluctant to have any contact with social services, even though they might be able to help. One parent explained:

'No, I wouldn't tell social services anything. They have threatened to take my children away, they have categorically said to me that we're not here for you, we're here for [child's name]. They come round here and have knocked on the door, come in and said "we're going to talk to your child in his bedroom and not you". I wasn't expecting them; how am I supposed to be on top form?' (P10).

Other parents described their experience in terms of being under scrutiny and feeling under pressure to prove that they were able to fulfil their role as a parent. Describing this, one parent said:

'They simply 'observed' myself and [daughter]; they were looking to see if she was safe; what use is that? What they should've been doing is helping me help [daughter].' (P1).

Some parents also described how they felt bullied by social services, and felt threatened that if they were to ask for a great deal of support, there could be consequences for parents and children. One parent described their experience:

'I felt very strongly threatened; I think it was one of those situations where you had to be there to hear what was said and the way it was said and in the context that it was said. I did find it quite threatening with the intention to intimidate so

that I wouldn't ask or I wouldn't complain or she didn't have to do anything about it.' (P14).

One parent described the sometimes emotive nature of the help and support that social services provided for parents. One parent explained that due to the dynamics of her particular family circumstance, in which parents had become divorced under highly stressful conditions, social services had become a vehicle through which parents were attempting to gain custody of the child. Describing this, she explained:

'My ex-husband thinks I'm making all this up; he plays the professionals off against me, it's him who tells them I can't cope and they don't understand what he's doing, trying to get his son back, and they just absorb it all and use it against me. I've been accused of all sorts of extremely upsetting things which I would never, ever do, but they still come straight round here threatening to take my son away.' (P10).

4.8 Housing adaptations and equipment

Eleven parents (69%) indicated that they had had adaptations made to their homes specifically to help them in their parenting role. Of the parents who said they had had adaptations, three people stated what these were:

- two parents had had a shower chair and grab rails installed and had also had their kitchen units lowered;
- three parents had had door widening and layout changes.

One other parent indicated that she was going to have a ceiling hoist and special bed fitted. Some parents indicated that they had funded these adaptations whilst others indicated that they had had some assistance from social services. When asked whether they knew where to get advice concerning housing adaptations, 12 parents (75%) responded positively and four (25%) said no. Six parents (38%) indicated that they also had special equipment in the home to help them with their parenting role but did not elaborate on what equipment they had. Five people indicated that their equipment was regularly reviewed.

4.9 Leisure and other social activities

Parents were asked about their experience of visiting sporting and leisure venues to do things with their children. One parent did not answer this question. Table 4.9.1 shows that the majority of parents (60%, 9) rated their experience as satisfactory, with a minority rating it positively (13%, 2) or negatively/very negatively (26%, 4). It was evident from parents' comments that for some, their experience of modern venues was very positive, with access having been adapted for wheelchairs, even

large wheelchairs. Some parents thought that the nature of their disability precluded them from participating in leisure and sporting activities with their children.

Table 4.9.1 Parents' experience of visiting social or leisure venues for children to participate

	n	%
Very positive	0	0
Positive	2	13
Satisfactory	9	60
Negative	2	13
Very negative	2	13
Total	15	100

A second question was asked in relation to parents' experience of leisure and sporting venues when they themselves wanted to participate. Two parents did not answer this question. Table 4.9.2 shows that parents' responses show a similar pattern to that for Table 4.9.1, indicating that if facilities were adapted to accommodate disabled parents with children they were also likely to be adapted to enable disabled parents' own participation.

Table 4.9.2 Parents' experience of visiting social or leisure venues to participate themselves

	n	%
Very positive	0	0
Positive	2	14
Satisfactory	8	57
Negative	2	14
Very negative	2	14
Total	14	100

4.10 Parents' overall rating of the support in Cheshire

Table 4.10.1 shows parents' overall rating of the support given to disabled parents in Cheshire. Responses indicate that three quarters (75%, 12 parents) of parents thought that support was satisfactory or worse and only a minority rated support as either good or excellent (25%, 4)

Table 4.10.1 Parents' overall rating of the support given to disabled parents in Cheshire

	n	%
Excellent	1	6
Good	3	19
Satisfactory	2	13
Poor	4	25
Very poor	6	38
Total	16	100

4.11 Conclusion

The qualitative and quantitative data presented in this Chapter provide a rich description of disabled parents' perspectives on their relationships with social, education and community care services in Cheshire. Furthermore, the data give some insight into the processes through which services may be experienced as good or poor. The findings can be used to provide a potentially valuable evidence base to inform local developments in policy and practice aimed at improving disabled parents experiences of services. These issues are explored in more detail in Chapter 5.

All sectors were seen as having limitations. Health services, perhaps because of the more technical aspects of provision, were often particularly difficult to negotiate. Kroll et al. (2006) have noted the long standing barriers to primary care for disabled people that have remained unchanged over time, consistent with the social model of disability in that physical and social barriers limit full participation for people with impairment.

Chapter 5

Discussion

5.1 Introduction

This was a small-scale study that was, to some degree, limited by the number of research participants recruited. Whilst the sample was relatively diverse in terms of age, family size and structure, and type of disability, its composition reveals some evident gaps: few disabled fathers, parents with severe learning difficulties, profound deafness, visual impairment or severe mental illness were recruited to the study. Increasing the diversity of the sample may have increased the diversity and nature of issues discussed. Whilst the views expressed in this study cannot be taken as representative of disabled parents' views more generally, they have validity and legitimacy as research evidence in that they illustrate the kinds of experiences that disabled parents in similar situations, using similar services may well experience. In fact, the kinds of experiences described by the disabled parents in this study are similar to those reported by other researchers (see for example Goodinge, 2000; Kroll, et al., 2006; Morris, 2003; Wates, 2003). This indicates that local social, education and community services are no better (and possibly no worse) than provision elsewhere in the country as well as further afield. Furthermore, it was also evident that the kinds of difficulties experienced by the disabled parents in this study were similar across the different service sectors, indicative of common 'barriers' and, possibly, common solutions. There was an exception to this: there was some indication that participating in leisure and social activities was somewhat easier than for other services. This may be because of the commercial nature of these venues and activities. However, the current study suggests that in spite of an increasing emphasis on supporting parents to care for their children, including disabled parents, and some illustrations of good practice, translating these policy aspirations into practice remains a challenge at a local level. This Chapter explores the implications of the findings for the development of policy and practice in order to provide some signposts for thinking about change at a local level.

5.2 Key conclusions: the social model of disability

The evidence from this study suggests that disabled parents' experiences are mixed. In terms of understanding why some services in some circumstances fully meet disabled parents expectations and requirements and others fall short, it is useful to draw on the social model of disability. Thus, by refocusing attention away from

individual pathology, the root cause of problems can be located in the social and physical environment. It is also useful to focus on this model because the findings from this study suggest that the problems disabled *parents* experience are those that disabled *people* face. However, being a disabled parent increases the complexity of daily life because of caring responsibilities for another individual, as well as taking parents into domains that are not inhabited by those who do not have to care for children. There is a further common factor that unites all people using public services and that is the quality of service provision experienced by any one using, for example, an NHS hospital.

Parents' accounts of their experiences revealed that their full participation in family life and the extent to which they can carry out their parenting role was compromised – and sometimes severely so – by the organisation and structure of buildings, facilities and transportation. This meant that for some parents the simplest of journeys to the GP for example, became a series of obstacles that had to be negotiated. One consequence of this is that disabled parents require considerable assertiveness to ask for 'special' treatment; that is to say, in an environment where the norm is to be non-disabled, exceptions have to be asked for if the particular requirements of those parents who are disabled are to be accommodated.

With recent changes to legislation requiring public bodies to make their environments more disabled friendly, this may go some ways towards addressing some of the issues to do with access. However, for those parents who do not have a physical disability in which mobility is the key issue, improving access is a more complex issue. The variety of disabilities, including learning difficulties and mental health problems, as well as different circumstances (for example the number and age of children parents have, the age at which parents became disabled and so on) creates individual requirements that often require an individual service response.

Given that services are delivered by practitioners, a key influence on the quality of the service experience for users is the care and attention they receive from those with whom they come into contact. The findings from this study suggest that practitioners were often the difference between disabled parents feeling welcomed, encouraged, reassured and supported in an empowering way, and not so. In fact, practitioners were sometimes the ones who helped disabled parents overcome the physical and environmental barriers they experienced. Conversely, it is likely that some practitioners might themselves construct barriers even when working in a

facilitative environment. This suggests that because professional practice is the vehicle through which policy is enacted, it is the key to bringing about change in local service provision towards a model that is flexible and responsive to the particularity of each disabled parent's situation. However, as Kroll et al. argue (2006) these process barriers – that is to say, a lack of disability-related provider knowledge, respect and skilled assistance – may be more difficult to challenge and change than those structural-environmental ones. The social model of disability helps explain the barriers to social exclusion that disabled parents can encounter by locating them in the social and political context of policy and practice and, in so doing, can be used to think through possible solutions for improvement.

Whilst the quality of practitioner-client interaction is a key factor in generating positive experiences for disabled people, as suggested above, professional practice is itself constrained by the particular social, economic and political context. Thus, practitioners are free to act but not in circumstances of their own making. This analysis suggests that, not only is it important to identify local and national constraints that are mediated through the particular policy context at any one time, but also to identify what are the realistic options for discretion and influence at a local level. This point is explored more fully below.

5.3 Implications for policy and practice

The findings from this study point to the need for systems and services that are more responsive to the diverse needs of disabled parents. As far as disabled parents are concerned, and in line with the current emphasis in government policy, this means that the commitment should be towards supporting them primarily as *parents*. This means that local support and community services need to be family-centred in order to provide an holistic approach to supporting disabled parents, in which their relationship with their children is seen as of paramount importance. Whilst the national policy context is supportive of this happening, translating this into everyday policy and practice at a local level would appear to be difficult. However, there are a number of tangible steps that could be taken to challenge the prevailing climate in which disabled parents have to fight for various entitlements.

Firstly, the value of direct payments is indicated in this study; having direct payments was evaluated by parents positively and can be seen as a genuinely empowering policy development. However, it seems to be the case that there is still some way to go if all those who are entitled to direct payments are routinely informed about them,

have opportunities to discuss their concerns and are supported appropriately when they embark on the process. Enabling disabled parents to prepare adequately for the community care assessment process through, for example, the routine use of the disabled parents' assessment tool developed by CDF, might be a valuable development.

Secondly, in order to avoid the separation of disabled parents' personal needs from those of their families, the community care assessment process should be reviewed. Thus, in circumstances where the parent is disabled, a process that ensures a family-centred assessment is carried out would go some way towards ensuring that the assessment is holistic. Furthermore, it is likely that this will be a more effective and efficient process for all parties.

Thirdly, addressing the process factors (Kroll et al., 2006) that can undermine the realisation of disabled parents' support needs, requires attention to staff development and training that prioritises disability-related knowledge, skilled assistance and the management of social relations based on dignity and respect. The challenge of this should not be underestimated, particularly given that staff development and training budgets are often limited and under threat in circumstances of resource constraints. Furthermore, opportunities for staff development can be limited when there are staff shortages. However, it is unlikely that there will be any fundamental improvements for disabled parents if changes in many practitioners' predispositions towards their practice are not forthcoming; staff development could be a vehicle for bringing about this shift. It is likely that this is one of the most important factors if responsive and flexible services are to develop. The designation of key staff with responsibility for disabled parents in organisations might be one outcome from this process.

Finally, there is a key role for the voluntary sector in facilitating change. Organisations such as CDF are in the best possible position to advocate on disabled parents' behalf. Dialogue between public sector organisations and relevant voluntary sector organisations has the potential to build on the relationships that are evident at a local level by considering how best to take the agenda forward.

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Appendix 1
Invitation letter to parents

Date

Dear Parent,

I am writing on behalf of the Centre for Public Health Research (CPHR) at the University of Chester, who would like to invite you to take part in a research study. The purpose of the study is to obtain your views and experiences of the support that is available for disabled parents, as well as your experiences of being able to access community and support services in Cheshire. The study aims to use your views and experiences to look at the support that is currently available to disabled parents in Cheshire. The research has been commissioned by the Cheshire Disabilities Federation (CDF) and is funded by the Cheshire Children's Fund.

Your part in the study would involve taking part in a telephone interview with a researcher to talk about your views and experiences of the support that you have received as a disabled parent, as well as your experience of accessing services. It is anticipated that this will take about 30 minutes. There is no obligation to take part in the research study and if you feel unable to take part at the present time, please do not feel under any pressure to do so. However, if you would like the opportunity to express your views and experience of the support available to help disabled parents, please fill in and return the 'consent to be contacted' slip, using the freepost envelope enclosed with this letter. If you decide to take part you are still free to withdraw at any time and without giving a reason.

Once this has been received you will be contacted by a trained researcher from the CPHR to take part in an interview over the telephone. Enclosed with this letter is a Participant Information Sheet which provides more details about the research study. If you have any further questions about taking part, you can contact the researcher on the number provided on the enclosed Participant Information Sheet.

Thank you for taking the time to read this letter.

Yours sincerely,

James Caiels
Researcher
University of Chester

Appendix 2
Participant information sheet

Participant Information Sheet

The views and experiences of disabled parents in Cheshire

You are being invited to take part in a research study by participating in a telephone interview about your experiences and views on being a disabled parent. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The aim of the study is to explore the experiences and perceptions of disabled parents in relation to accessing and using social and community services. The focus will be on finding out disabled parents' views on the services and support available to them and how accessible they are. The findings from the study may help to develop services and support for disabled parents.

Who is organising and funding the research?

The research has been commissioned by the Cheshire Disabilities Federation (CDF) and is funded by the Cheshire Children's Fund. Researchers from the Centre for Public Health Research at the University of Chester are carrying out the study.

Why have I been chosen?

You have been chosen because you are a disabled parent. We are very interested to find out about your views and experiences.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your relationship with any services you use or support you receive.

What will happen to me if I take part?

If you decide to take part, you should keep this information sheet, and sign and return the tear-off slip at the base using the pre-paid envelope provided. Alternatively you can contact the researcher by phone or email to register your interest. This will give your consent for a researcher from the Centre for Public Health Research at the University of Chester to contact you for a telephone interview. During this interview, you will have the opportunity to raise and discuss your views and experiences of the support available to you as a disabled parent in Cheshire, as well as your experiences of accessing services. The interview will last about 30 minutes and with your permission it will be recorded and your answers will be noted and then stored on computer. A written report of the study will be produced and some interview material will be used in this report. All interview material used will be anonymised and

individuals' details will be kept confidential, so no names or identifying details will be used in the report. Only researchers working on the study will have access to the information you provide.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks foreseen in taking part in the study. However, you will be free to stop the interview at any time without giving a reason or affecting your relationship with any services you use or support you receive.

What are the possible benefits of taking part?

You may appreciate the opportunity to share and discuss your experiences and to put forward your views.

Will my taking part in this study be kept confidential?

Nobody need know if you decide to take part in this study. Taking part is strictly confidential and no names or details that could identify you would ever be used in any written or verbal report of the study. No information will be passed to any other parties.

What will happen to the results of the research study?

A written report of the study will be produced but, as already explained, nobody who takes part in the study will be identifiable.

Who may I contact for further information?

If you would like more information about the research before you decide whether or not you would be willing to take part, or you wish to register your interest in taking part without using the slip provided below, please contact James Caiels on 01244 512058 or write to James at the Centre for Public Health Research, University of Chester, Parkgate Road, Chester, CH1 4BJ. You can also email James at j.caiels@chester.ac.uk

Thank you for your interest in this research.

✂.....

Please tear off here and return this slip in the pre-paid envelope.

I agree to a researcher contacting me to arrange for me to take part in an informal telephone interview in due course.

Name:

Phone Number:

Date:

Signature: _____

Appendix 3
Questionnaire for the Deafness Support Network

7. If yes, what is the nature of their condition / impairment / illness / disability?
(please state)

8. Does your child or your children live with you all the time, or are they partly cared for by someone else (such as another family member) on a regular basis?

They live with me all the time ☺

They are partly cared for by someone else on a regular basis ☺

9. Which of the following best describes your situation?

Married or living with partner ☺

Single parent ☺

Other (please state) ☺

When thinking about your answers to the following questions, it may be useful to think about some of the following:

- Access.
- The way you and your children have been treated.
- Whether or not you have been generally helped?
- Whether or not you have generally got what you wanted?
- Whether or not you have had access to the information you wanted?
- Whether or not you've ever been told you couldn't have things because there were insufficient resources? For example, have people responded to your requests if/when you have had any?
- Whether or not you feel you are able to participate as equally as other parents?

School and early learning

10. How would you describe your experiences as a parent, of taking part in your child's or children's education?

Very positive ☺

Positive ☺

Satisfactory ☺

Negative ☺

Very negative ☺

By this we mean whether or not you feel able to communicate with the school and how the school responds to your needs as a disabled or D/deaf parent.

11. Using examples, could you explain your answer?

12. How would you describe your relationship with the school and with staff at the school?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺

By this we mean whether or not you feel able to communicate with the school and how the school responds to your needs as a disabled or D/deaf parent.

13. Using examples, could you explain your answer?

14. From the perspective of someone with a particular condition, illness or impairment, could you describe your experience of attending pre-school or early years activities such as 'Mums and Tots'?

- Very positive ☺
- Positive ☺
- Satisfactory ☺
- Negative ☺
- Very negative ☺
- Not applicable ☺

15. Using examples, could you explain your answer?

16. Would you say you are able to take part in school activities (for example, school trips, helping out in the classroom, parents evenings etc) as much as other parents?

- Yes ☺
- No ☺
- Not sure ☺

17. Using examples, could you explain your answer?

18. In your view, has your child, or any of your children, experienced any form of bullying or harassment whilst at school because of your condition / illness / impairment / disability?

- Yes ⇒ (go to **19**)
- No ⇒ (go to **20**)

19. If yes, how old were the children at the time? _____

Childcare

20. From the perspective of someone with a particular condition, illness or impairment, how would you rate being able to access childcare?

- Extremely easy ⇒
- Easy ⇒
- It is okay ⇒
- Difficult ⇒
- Extremely difficult ⇒
- Not applicable ⇒

21. Using examples, could you explain your answer?

22. From the perspective of someone with a particular condition, illness or impairment, how would you rate being able to find **affordable** childcare?

- Extremely easy ⇒
- Easy ⇒
- It is okay ⇒
- Difficult ⇒
- Extremely difficult ⇒
- Not applicable ⇒

23. Using examples, could you explain your answer?

24. If adequate childcare was provided, do you feel you would be more able to take part in community activities?

- Yes, I think childcare would help ⇒
- I'm not sure ⇒
- No, I receive adequate childcare ⇒

Transport

25. What form of transport do you mostly use to get out and about with your children?

- Car ☺
If you use a car, do you drive yourself or does someone else drive you?
I drive myself ☺ Someone else drives me ☺
If someone else drives you, who is this? (Partner etc) _____
Taxi ☺
Bus ☺
Train ☺
By foot ☺
Cycle ☺
Other (please state) _____

26. From the perspective of someone with a particular condition, illness or impairment, how easy would you say it is to get around with your child or your children?

- Extremely easy ☺
Easy ☺
It is okay ☺
Difficult ☺
Extremely difficult ☺

27. Using examples, could you explain your answer?

28. If you do use public transport, what are your experiences of it? Do you feel able to use public transport easily for yourself and your child or children?

29. Do you personally take your child(ren) to school?

- Yes ☺ (go to **30**)
No ☺ (go to **31**)

30. If yes, how do you do this (what form of transport) and what is your experience of this? How easy or difficult do you find it?

31. If no, is it by choice that you do not take them to school, or would you like to be able to? Are other factors involved? (Please explain)

Health services

In relation to the following, it may be useful to think about the occasions when you have taken your children to see a health professional and also when you yourself are using health services, but have to bring your children with you.

32. From the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your GP?

Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺

33. Using examples, could you explain your answer? What about your relationship with the nurses or other health professionals at the surgery?

34. From the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of attending hospital as an outpatient?

Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺
Not applicable ☺

35. Using examples, could you explain your answer?

36. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of staying overnight in hospital?

Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺
Not applicable ☺

37. Using examples, could you explain your answer?

38. From the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your health visitor?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

39. Using examples, could you explain your answer?

40. From the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your midwife?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

41. Using examples, could you explain your answer?

42. From the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of taking part in antenatal classes?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

43. Using examples, could you explain your answer? What was your initial meeting with the antenatal health professional like? Do you have any experiences of any other specific clinics? If so, what were these like?

Social Services

45. Have you had a community care assessment? Yes ☞ (go to **47**)
No ☞ (go to **46**)

46. If no, could you say why you have not had one? Is there anything specific that has stopped you from approaching social services for help? (go to **54**)

47. Do you think your parenting needs were taken into account during your care assessment? Yes No Not sure
☞ ☞ ☞

48. Could you please explain your answer? If yes, how were they taken into account, what steps were taken? If no, could you explain how your parenting needs were not taken into account, what was overlooked or not considered?

49. Were you encouraged to have your child stay with someone else during your care assessment?

Yes ☞ (go to **50**)
No ☞ (go to **51**)

50. If yes, how did you feel about this?

51. Can you think of anything that would have made the whole process any easier? Yes No
☞ ☞

52. If yes, could you say what these are?

53. Do you think it would be useful if you could use a toolkit yourself that helped you identify your support needs before you had your community care assessment?

Yes ☐ No ☐ Not sure ☐

54. Have you been offered any support to help you with your parenting responsibilities?

Yes ☐ (go to **55**)

No ☐ (go to **56**)

55. If yes, could you say what these are?

56. Have you had any contact with children's social services related to your parenting needs?

Yes ☐ (go to **57**)

No ☐ (go to **58**)

57. What is your experience of these? Do they complement adult services? Were you able to access these easily? Did you get good, helpful advice? Were they worried about your ability to be a parent? Were they worried about you being too reliant on your child or children? (go to **59**).

58. Is there any reason why you have not tried to get support from children's social services? Has anything stopped you from doing this?

59. Do you now receive any services that help you with your parenting?

Yes ☐ (go to **60**)

No ☐ (go to **62**)

60. If yes, could you say what kind of help you receive?

67. If you are on direct payments, can you say how it has affected you and what difference using direct payments has made to your life?

68. Did you know that you can use direct payments for help with your parenting role?

Yes ☐
No ☐

Housing adaptations and equipment

	Yes	No
69. Do you know where to get advice about having housing adaptations or equipment specifically relating to your parenting needs?	☐	☐

70. Have you had any **adaptations** made to your home in order to support you in your role as a parent?

Yes ☐ (go to **71**)
No ☐ (go to **72**)

71. If yes could you say what these are and how they help you?

72. Do you have any **equipment** in your home in order to support you in your role as a parent?

Yes ☐ (go to **73**)
No ☐ (go to **75**)

73. If yes could you say what these are and how they help you?

	Yes	No	Not Applicable
74. Is the equipment you use regularly reviewed as your needs as a parent change?	☐	☐	☐

Leisure and other social activities

75. From the perspective of someone with a particular condition, illness or impairment, could you describe your experience of visiting sporting or leisure venues for your child or your children to participate in?	Very positive ☐
	Positive ☐
	Satisfactory ☐
	Negative ☐
	Very negative ☐

76. Using examples, could you explain your answer?

77. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, could you describe your experience of visiting sporting or leisure venues for **you to participate in** with your children (e.g. swimming)?

- Very positive ☺
- Positive ☺
- Satisfactory ☺
- Negative ☺
- Very negative ☺

78. Using examples, could you explain your answer?

Support for disabled parents

79. How would you rate the support that is **offered** to disabled parents in Cheshire overall?

- Excellent ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very Poor ☺

80. How would you rate the support that is **given** to disabled parents in Cheshire overall?

- Excellent ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very Poor ☺

81. Have you heard of any of the following organisations?

	Yes	No
Disabled Parents Network (DPN)	☺	☺
Disability, Pregnancy and Parenthood International (DPPI)	☺	☺
Cheshire Disabilities Federation (CDF)	☺	☺

Thank you for your time.

Appendix 4
Questionnaire for disabled parents

**The views and experiences of disabled parents in Cheshire
Telephone interview schedule**

A little bit of information about yourself and your family

1. Are you: Male ☐
 Female ☐
2. How old are you? 17 or younger ☐ 45-54 ☐
 18-24 ☐ 55-64 ☐
 25-34 ☐ 65 or over ☐
 35-44 ☐
3. What is the nature of your condition / impairment / illness / disability?
(please state)
-

4. How many children do you have?

1 ☐ 2 ☐ 3 ☐ 4 or more ☐

5. Are you the only carer for your child(ren) or are you a co-carer?

By this we mean do you look after your child(ren) by yourself or is there someone else who helps (such as your husband or wife or partner etc).

Only carer ☐ (go to **8**) Co-carer ☐ (go to **6**)

6. If you are a co-carer, does your partner have a disability or any condition / impairment / illness?

Yes ☐ (go to **7**) No ☐ (go to **8**) Not applicable ☐

7. If yes, what is the nature of their condition / impairment / illness / disability?
(please state)
-

8. Do your child(ren) live with you all the time or are they partly cared for by someone else (such as another family member) on a regular basis?

They live with me all the time ☐

They are partly cared for by someone else on a regular basis ☐

9. Which of the following best describes your situation?

- Married or living with partner ☒
- Single parent ☒
- Other (please state) ☒
-

School and early learning

In relation to the following, please think about: access, service, the way you / family members have been treated, whether or not you were generally helped and got what you wanted, whether you have had access to information, whether you were told you couldn't have things because there were insufficient resources, whether the school is responsive to your needs, for example, do they respond to your requests if/when you have any? Do you feel that you are able to participate in the life of the school?

10. How would you describe your experiences as a parent, of taking part in your child's or children's education?

- Very positive ☒
- Positive ☒
- Satisfactory ☒
- Negative ☒
- Very negative ☒

By this we mean, do you feel you have been able to take an active part in the school community and have you felt involved in decisions regarding your child's or children's education?

11. Using examples, could you explain your answer? Have you found any differences between schools and / or your children?

12. How would you describe your relationship with the school and with staff at the school?

- Very good ☒
- Good ☒
- Satisfactory ☒
- Poor ☒
- Very poor ☒

By this we mean whether or not you feel able to communicate with the school and how receptive the school is to your needs as a disabled parent.

13. Using examples, could you explain your answer?

14. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, could you describe your experience of attending pre-school or early years activities such as 'Mums and Tots'?

Very positive ☺
Positive ☺
Satisfactory ☺
Negative ☺
Very negative ☺

15. Using examples, could you explain your answer?

16. Would you say you are able to take part in school activities (for example, school trips, helping out in the classroom, parents evenings etc) as much as, or equal to, other parents?

Yes ☺
No ☺
Not sure ☺

17. Using examples, could you explain your answer?

18. In your view, has your child, or any of your children, experienced any form of bullying or harassment whilst at school because of your condition / illness / impairment / disability?

Yes ☺ (go to **19**)
No ☺ (go to **20**)

19. If yes, how old were the children at the time? _____

Childcare

In relation to the following, please think about: access, service, the way you / family members have been treated, whether or not you were generally helped and got what you wanted, whether you have had access to information, whether you were told you couldn't have things because there were insufficient resources.

20. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you rate being able to access childcare?

Extremely easy ☺
Easy ☺
It is okay ☺
Difficult ☺
Extremely difficult ☺

21. Using examples, could you explain your answer?

22. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you rate being able to find affordable childcare?

- Extremely easy ☺
- Easy ☺
- It is okay ☺
- Difficult ☺
- Extremely difficult ☺

23. Using examples, could you explain your answer?

24. If adequate childcare was provided, do you feel you would be more able to take part in community activities?

- Yes, I think childcare would help ☺
- I'm not sure ☺
- No, I receive adequate childcare ☺

Transport

In relation to the following, please think about: accessibility, cost, the way you / family members have been treated, and the ease with which you feel able to get out and about.

25. What form of transport do you mostly use to get out and about with your children?

- Car ☺
- If yes do you drive yourself or does someone else drive you?
 - I drive myself ☺
 - Someone else drives me ☺
 - Who is this? (Partner etc) _____
- Taxi ☺
- Bus ☺
- Train ☺
- By foot ☺
- Cycle ☺
- Other (please state) _____

26. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how easy would you say it is to get around with your child(ren)?

- Extremely easy ☺
- Easy ☺
- It is okay ☺
- Difficult ☺
- Extremely difficult ☺

27. Using examples, could you explain your answer?

28. If you do use public transport, what are your experiences of it? Do you feel able to use public transport easily for yourself and your child(ren)?

29. Do you personally take your child(ren) to school?

- Yes ☺ (go to **30**)
- No ☺ (go to **31**)

30. If yes, how do you do this (what form of transport) and what is your experience of this? How easy or difficult do you find it?

31. If no, is it by choice that you do not take them to school, or would you like to be able to? Are other factors involved? (Please explain)

Health services

In relation to the following, please think about: access, service, the way you / family members have been treated, whether or not you were generally helped and got what you wanted, whether you have had access to information, whether you were told you couldn't have things because there were insufficient resources. Also, think about the occasions when you are taking your children to see a health professional and when you yourself are using health services but have to bring your children with you, as there is no-one else who can look after them.

- 32.** As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your GP?
- Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺

- 33.** Using examples, could you explain your answer? What about your relationship with the nurses or other health professionals at the surgery?

- 34.** As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of attending hospital as an outpatient?
- Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺
Not applicable ☺

- 35.** Using examples, could you explain your answer?

- 36.** As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of staying overnight in hospital?
- Very good ☺
Good ☺
Satisfactory ☺
Poor ☺
Very poor ☺
Not applicable ☺

37. Using examples, could you explain your answer?

38. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your health visitor?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

39. Using examples, could you explain your answer?

40. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your relationship with your midwife?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

41. Using examples, could you explain your answer?

42. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, how would you describe your experience of taking part in antenatal classes?

- Very good ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very poor ☺
- Not applicable ☺

43. Using examples, could you explain your answer? What was your initial meeting with the antenatal health professional like? Do you have any experiences of any other specific clinics? If so, what were these like?

	Yes	No	Not Applicable
44. If you have a carer or personal assistant and have stayed overnight in hospital, were your carers able to stay with you outside of hospital visiting hours?	☐	☐	☐

Social Services

In relation to the following, please think about: access, service, the way you / family members have been treated, whether or not you were generally helped and got what you wanted, whether you have had access to information, whether you were told you couldn't have things because there were insufficient resources.

45. Have you had a community care assessment?	Yes	☐ (go to 47)
	No	☐ (go to 46)

46. If no, could you say why you have not had one? Is there anything specific that has stopped you from approaching social services for help?

	Yes	No	Not sure
47. Do you think your parenting needs were taken into account during your care assessment?	☐	☐	☐

48. Could you please explain your answer? If yes, how were they taken into account, what steps were taken? If no, could you explain how your parenting needs were not taken into account, what was overlooked or discounted?

49. Were you encouraged to have your child stay with someone else during your care assessment?

Yes	☐ (go to 50)
No	☐ (go to 51)

50. If yes, how did you feel about this?

51. Can you think of anything that would have made the whole process any easier? Yes No
 ☐ ☐

52. If yes, could you say what these are?

53. Do you think it would be useful if you could use a toolkit yourself that helped you identify your support needs before you had your community care assessment?

Yes ☐ No ☐ Not sure ☐

If yes provide details.

54. Have you been offered any support to help you with your parenting responsibilities?

Yes ☐ (go to **55**)
No ☐ (go to **56**)

55. If yes, could you say what these are?

56. Have you had any contact with children's social services related to your parenting needs?

Yes ☐ (go to **57**)
No ☐ (go to **58**)

57. What is your experience of these? Do they complement adult services? Were you able to access these easily? Did you get good, helpful advice? Were they concerned about your ability to be a parent? Were they concerned about your child or children being 'young carers'? (go to **59**).

58. Is there any reason why you have not tried to get support from children's social services? Has anything stopped you from doing this?

59. Do you now receive any services that help you with your parenting?

Yes ⇒ (go to **60**)

No ⇒ (go to **62**)

60. If yes, could you say what kind of help you receive?

61. How would you say you rate the help that you receive?

Very good ⇒

Good ⇒

Satisfactory ⇒

Poor ⇒

Very poor ⇒

62. Were you offered Direct Payments when you had your care assessment?
(This is the option for you to purchase some or all of the services you are eligible for directly yourself, using money provided by social services).

Yes ⇒ (go to **64**)

No ⇒ (go to **63**)

Direct Payments

63. Do you know about direct payments?

Yes ⇒

No ⇒

Not sure ⇒

64. Are you on direct payments?

Yes ⇒ (go to **67**)

No ⇒ (go to **65**)

65. If you are not on direct payments, can you say why?

I don't know anything about them ⇒

I don't know enough about them ⇒

I don't want to use them ⇒

I was told I couldn't have them ⇒

Other (please state)..... ⇒

66. Would you like more information about direct payments? (go to **68**)

- Yes ☐
- No ☐
- Not sure ☐

67. If you are on direct payments, can you say how it has affected you and what difference using direct payments has made to your life?

68. Did you know that you can use direct payments for help with your parenting role?

- Yes ☐
- No ☐

Housing adaptations and equipment

69. Do you know where to get advice about housing adaptations or equipment specifically relating to your parenting needs?

- | Yes | No |
|-----|----|
| ☐ | ☐ |

70. Have you had any adaptations made to your home in order to support you in your role as a parent?

- Yes ☐ (go to **71**)
- No ☐ (go to **72**)

71. If yes could you say what these are and how they help you?

72. Do you have any equipment in your home in order to support you in your role as a parent?

- Yes ☐ (go to **73**)
- No ☐ (go to **75**)

73. If yes could you say what these are and how they help you?

74. Is the equipment you use regularly reviewed as your needs as a parent change?

- | Yes | No | Not Applicable |
|-----|----|----------------|
| ☐ | ☐ | ☐ |

Leisure and other social activities

In relation to the following, please think about: access, service, the way you / family members have been treated, whether or not you were generally helped and got what you wanted, whether you have had access to information, whether you were told you couldn't have things because there were insufficient resources.

75. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, could you describe your experience of visiting sporting or leisure venues for your child(ren) to participate in?
- Very positive ☺
Positive ☺
Satisfactory ☺
Negative ☺
Very negative ☺

76. Using examples, could you explain your answer?

77. As a disabled parent, or from the perspective of someone with a particular condition, illness or impairment, could you describe your experience of visiting sporting or leisure venues for you to participate in with your children (e.g. swimming)?
- Very positive ☺
Positive ☺
Satisfactory ☺
Negative ☺
Very negative ☺

78. Using examples, could you explain your answer?

Support for disabled parents

79. How would you rate the support that is **offered** to disabled parents in Cheshire overall?

- Excellent ☺
Good ☺
Satisfactory ☺
Poor ☺
Very Poor ☺

80. How would you rate the support that is **given** to disabled parents in Cheshire overall?

- Excellent ☺
- Good ☺
- Satisfactory ☺
- Poor ☺
- Very Poor ☺

81. Have you heard of any of the following organisations?

	Yes	No
Disabled Parents Network (DPN)	☺	☺
Disability, Pregnancy and Parenthood International (DPPI)	☺	☺
Cheshire Disabilities Federation (CDF)	☺	☺

Thank you for your time.

Appendix 5
Consent form

CONSENT FORM
Parent Telephone Interview

Title of Project: Parenting in a family context of disability

Name of Researcher: James Caiels

Please tick box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.
3. I understand that with my permission the interview will be audio-taped.
4. I understand that my name and personal details will not be recorded.
5. I agree to take part in the above study.

Name of Interviewee Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Researcher Date Signature

