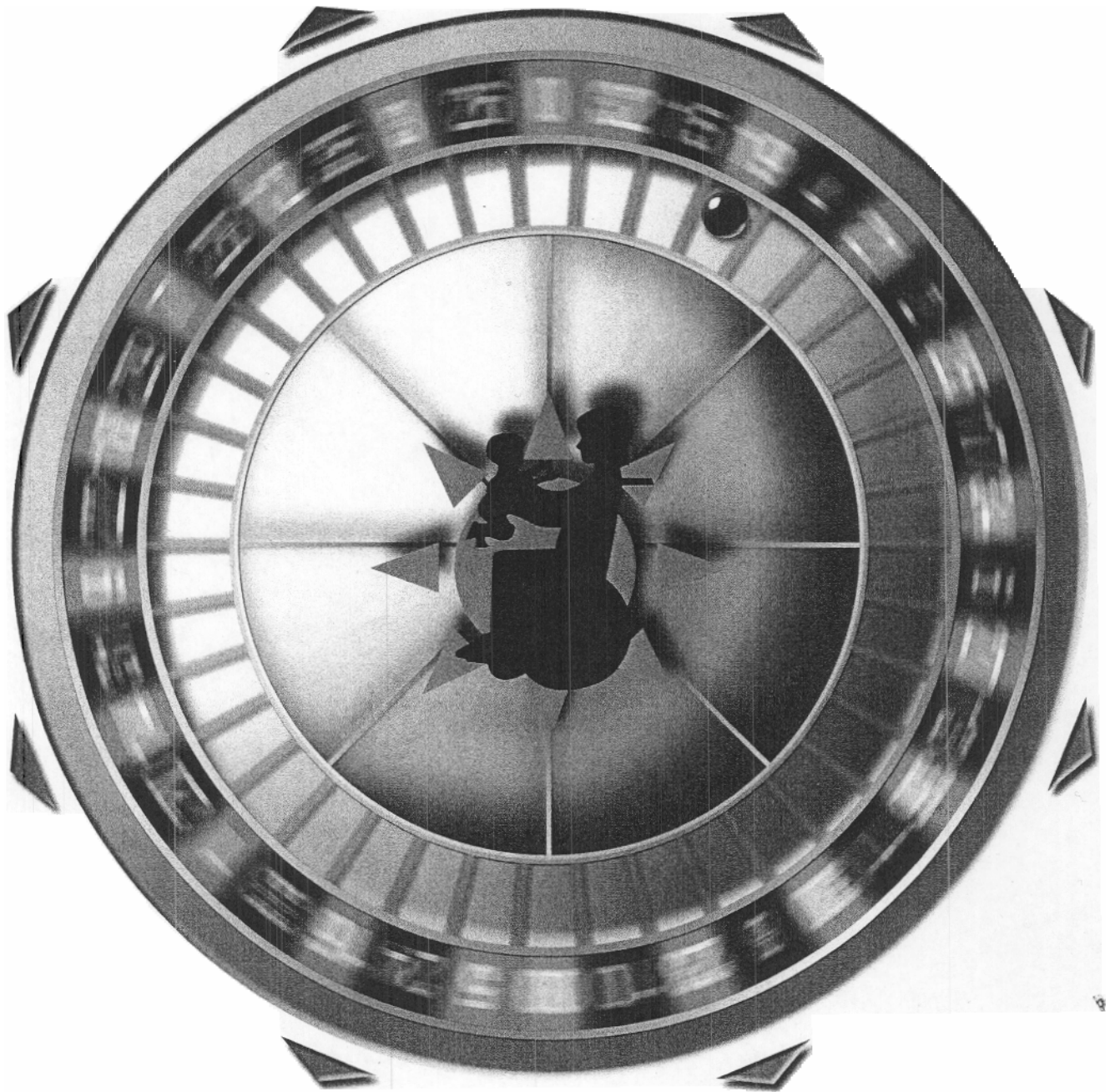


It shouldn't be down to luck

Results of a DPN consultation with disabled parents on access to information and services to support parenting

Michele Wates



Disabled Parents Network Handbook Project

It shouldn't be down to luck

**Results of a Disabled Parents Network
consultation with disabled parents on access to
information and services to
support parenting**

DPN wishes to thank all those parents who took time to contribute to the consultation in the hope that other parents will be able to get hold of better support.

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Executive Summary

Background

The 551 Inspection report *A Jigsaw of Services* (Goodinge 2000), along with much other research evidence over the past decade (Olsen and Wates 2003), points to the fact that it is very hard for parents with chronic illnesses, physical and/or sensory impairments, Deaf parents, those with learning difficulties or with particular mental health needs to access information, resources and support to help them fulfil their parenting responsibilities.

A consultation involving over 150 such parents, who in this report are collectively described as disabled parents, was carried out between May and December 2002 to inform preparation of a handbook by *Disabled Parents Network*, funded by the Department of Health.

Providing mainstreamed, planned support to disabled parents

Disabled parents report great difficulty in finding information and appropriate support when family needs change suddenly. Unless systems have the flexibility and responsiveness built in to respond quickly and appropriately at such times the consequences for disabled parents and their families can be serious.

The key question is how to plan and deliver service responses at both routine and crisis service entry points in ways that do not isolate and potentially stigmatise families but rather key parents in to mainstream parent education, maternity services and family support. Alongside inclusion in mainstream services, disabled parents also require access (via routes that they perceive as non-stigmatising), to specialist back up support services as relevant.

Prioritising practical supports

The extent to which disabled parents' practical support needs are met in relation to housing, adaptations, equipment, communication with schools etc, is crucial to children's welfare.

Parenting tasks and roles should be routinely included in any assessments for Community Care services.

The access of disabled adults to Community Care services, adaptations and equipment that will assist them to carry out their parenting responsibilities should be prioritised, in the best interests of children.

Direct payments

Direct payments are seen as putting flexibility into parents' hands, enabling them to set up assistance in the way that best suits their particular family needs, giving a better chance of building up continuity with assistants chosen by the families themselves and enabling parents to make changes as and when needs change.

Direct payments user support groups, acting in an advisory/ administrative/problem shooting role, have a key part to play in supporting the widest possible range of parents to use direct payments successfully.

Community supports

Disabled parents value peer support and community based networks extremely highly because they provide personal support, facilitate access to other resources and give parents opportunities to support other parents in similar situations.

Social inclusion only possible when practical steps are taken

The information and support needs of disabled parents will only be properly addressed if service providers in both voluntary and statutory sectors recognise that they have a responsibility to make sure their own information and services are inclusive of and accessible to disabled parents.

Information and services aimed at parents and families should routinely include issues relating to *disability I* whilst information aimed at disabled people should cover *parenting* issues. Information needs to be provided in a wide range of accessible formats.

Details of the consultation

The consultation was an opportunity survey, based on existing and available groups and networks supporting a range of parents with chronic illnesses, physical and/or sensory impairments, Deaf parents, those with learning difficulties or with particular mental health needs and disabled parents from black and ethnic minorities.

The consultation included analysis of 120 questionnaires, nine focus group meetings and several informal interviews. In all, over 150 disabled parents were involved in the consultation.

Introduction

'Providing support for parents to help them bring up their children better is at the core of the Government's family policy. However many disabled parents feel that this is still only a pipe dream for them.'

('A Jigsaw of Services'. Report of an SSI inspection of services to support disabled adults in their parenting role: Goodinge 2000)

Support to parents is crucial to children's welfare

Whilst it is crucial to the welfare of children that all parents are well supported, there has been much evidence over the past decade pointing to the fact that it is very hard for parents with chronic illnesses, physical and/or sensory impairments, Deaf parents, those with learning difficulties or with particular mental health needs to access information! resources and support to help them fulfil their parenting responsibilities.

For brevity, the parents outlined above are collectively described in this report as 'disabled parents'. It should be pointed out that not all of these groups of parents and indeed not all of the individuals involved in the consultation would use the term 'disabled' to describe themselves. For example, many Deaf activists make a deliberate and political point in distancing themselves from the term, believing that it implies an inappropriate judgement of their cultural and linguistic experience.

The term disabled, then, is being used to identify systematic disadvantage rather than to describe personal or group characteristics. Where a wide range of parents, broadly identifiable as disabled parents, are coming up against similar difficulties, this inclusive approach helps to clarify what it is in the way that services are organised and delivered that can act as a barrier to these groups of parents getting hold of support, to identify gaps in services and to look at unhelpful assumptions sometimes made by service providers. There will also be examples where particular groups of parents are at a disadvantage or where specialist inputs are especially important. These can be highlighted without losing sight of the links between groups.

Disabled parents falling through the gaps

In 1997 *Parents Too*, a group made up of organisations supporting disabled parents, and others working in the field of family rights, met with SSI Inspectors, representatives from the Department of Health and the Association of Directors of Social Services (ADSS) to talk about the difficulties disabled adults experience in getting hold of information, resources and support to help with parenting. Many disabled parents are hesitant to ask local authority (particularly social services departments) for help, fearing that their children will be labelled as 'children in

need' and that the service response will undermine their parenting role, identifying them as the 'problem' rather than supporting them with parenting.

Disabled parents report that when they seek help this is more likely to be seen as a children's service issue than as something that should be thought about as part of an adult support package, backed by appropriate specialist input. The issue of who is responsible for funding support gets tossed around like a hot potato between adults', children and families', carers' services, education, housing and health.

Considering the known links between disability and family poverty, the fact that family life is liable to change in both expected and unexpected ways, and the added complication of fluctuating health needs, there is a clear need, *Parents Too* argued, to develop services that are well joined up and that can respond holistically to family needs quickly, supportively and flexibly.

'A Jigsaw of Services'

In 1999 the 551 officers checked out the concerns expressed by *Parents Too* by carrying out an Inspection of services to support disabled adults in their parenting role in eight local authorities. Their report, called revealingly, '*A Jigsaw of Services*' (Goodinge 2000), said that support to disabled parents was indeed patchy.

The parent support needs of disabled adults frequently fall between adult service and services to children, resulting in delay or failure to provide a service (Goodinge 2000). Parenting tasks and roles are not routinely included in assessment procedures, and parents are very wary of asking for help. The Inspectors identify that part of the problem is the lack of information about services and support that is available to disabled parents and also that services are often not provided in ways that are sufficiently accessible to disabled parents. The Inspectors pointed out that local authorities have a duty under the Disability Discrimination Act to make sure that disabled parents can use their services:

*'... Service providers have to take reasonable steps to change policies, practices or procedures which make it impossible or unreasonably difficult for disabled people to use a service'.
(Goodinge 2000, Appendix C1.)*

The need for joined up working

The Inspectors recommend a major shift in the approach to working with disabled parents, including a recognition of the right of disabled people to be supported in fulfilling their roles and responsibilities as parents under Community Care legislation, and the development of policies and strategies to improve joined-up working across adults' and children's service divisions and between agencies:

'Best practice suggests that a disabled adult's care plan arising from a multi-professional needs-led assessment would include service provision for parenting tasks if appropriate and services would be provided from the relevant sources, including dedicated/skilled workers or agencies... '

(Goodinge 2000, 1.9)

Links between information and support

Whilst only a proportion of disabled parents would identify themselves as having significant support needs related to parenting and disability, all of them need access to the same range of information that other parents have, and in addition many have additional information needs relating to impairment.

The fact that disabled parents potentially have greater and more complex information needs, but in reality often have less access to information than their non-disabled counterparts puts them at a double disadvantage.

It is not always possible to separate out information and support as separate issues. Many of the comments made by parents showed how inextricably the two are linked; to provide timely information is a very supportive act, whilst good support is well informed and informative.

More than one parent expressed frustration that information was more forthcoming than support.

'Not difficult to find information but obtaining the help is diabolical! Getting information was OK but the level of support offered was inadequate.'

Generally, parents reported that it had been very difficult to get hold of the information they needed in relation to parenting. Where they succeeded many parents said that this had required a huge amount of energy and persistence on their part. Furthermore, information and support could not always be found in time to avoid serious difficulties.

'You don't know where to begin and no one tells you.'

'When I had my son I was totally unaware of any services to help me. I stayed in a destructive abusive marriage for longer than I should have because I didn't know there were alternatives. Sheer luck I came across DPN and other support agencies.'

'I had to find everything out for myself.'

'I've had to be very proactive.'

'There are good sources of information about but not always easy to obtain.'

'Good information is available but you have to push to get it.'

'Keep asking the same question to lots of different people; finally you'll find someone who will give you a useful answer!'

'I went to the chiropodist and asked them to cut my children's nails. Health services initially said, it's the parents' responsibility; I said that's why I'm here. It's my job to make sure my children are healthy and it's your job to support me to do just that.'

Besides Community Care legislation, a number of parents mentioned the 1995 Disability Discrimination Act.

'My needs & preferences should be taken into account.'

'Get social services involved -don't be put off -they have to meet your needs.'

'You've got to know your rights and your child's rights. E.g., antenatal class, school etc are obliged to address the access issues. Good thing about DDA is that it gives you a basis for insisting on your rights.'

'Wish DDA had been passed earlier. You just have to mention social inclusion and it can be effective.'

'When we became parents in the '60s there was no CSDP Act 1970. There was no information for disabled people then, parents or not.'

The need for a disabled parents' handbook

There are handbooks on rights, benefits and services for disabled people but these rarely cover parenting. At the same time, information aimed at parents and families rarely covers disability. It is hoped that having a handbook aimed specifically at disabled parents will make it easier for parents to get hold of information and support.

Disabled Parents Network (DPN) asked the Department of Health for funding to produce a handbook which would for the first time collect together information and support to disabled parents from a wide range of sources including health and social services, parent education, family welfare, education and sources of support

in the community. The intention is to make this information as easy as possible for parents to access and understand.

Developing services that include all parents

The consultation findings underline that producing a handbook is not the whole or the only answer to meeting the support and information needs of disabled parents. Even if all disabled parents knew about the existence of specialist support organisations such as DPN and DPPi (Disability, Pregnancy and Parenthood international) (see Appendix C); these organisations could not possibly meet the demand alone. The information and support needs of disabled parents can only be properly addressed if service providers in the voluntary and statutory sector recognise that they have a responsibility to make sure their own information and services are inclusive of and accessible to disabled parents.

The findings will inform preparation of a handbook for disabled parents but they will also be useful to service providers in both the statutory and voluntary sectors who are seeking to make their services more inclusive.

Why consult with disabled parents?

The natural place to start with finding out what should be included in the handbook and what else could be done to improve disabled parents' access to information was to ask parents directly about their experiences. The aim was to identify useful sources of information and support and at the same time to find out whether there were particular points at which parents had experienced difficulty or were not happy with what was available. '

The aim was also to check out whether what the 55I said in respect of social services departments (Goodinge 2000) applies across other agencies and the voluntary sector. Were there any useful clues in what disabled parents said about how to establish effective joined up working and what was the part played by the voluntary sector and informal support networks?

How the consultation was carried out

The consultation took place between May and December 2002. This was an opportunity survey, based on existing and available groups and networks, rather than a randomised, large-scale study.

A questionnaire (see Appendix A) was sent out to 240 members of Disabled Parents Network. Over a third of these were returned. This is a high rate of return on a postal questionnaire. This and the evident time and care that had been given to responding to the questions, with additional notes and comments added in many cases, showed a very positive and encouraging level of engagement on the part of DPN's membership. However these initial responses showed the need to broaden the scope of the consultation in order to collect more information about certain issues and to hear more from groups under-represented in the DPN responses.

Targeting under represented groups

Further questionnaires were targeted at disabled parents from black and ethnic minorities, single fathers, parents with learning difficulties, Deaf parents and those with mental health issues. This was mainly done by making contact with relevant local and national support networks. In addition I visited nine existing groups of parents to talk with them about the handbook and their experience of getting hold of information and support. These included four general disabled parents' groups, a group attached to a family project that supported parents with mental health difficulties, two groups of parents with learning difficulties, a group for users of direct payments and a group of parents with visual impairments.

Comments made at a meeting of disabled parents organised by Parentline Plus and funded by the Joseph Rowntree Foundation in January 2003 have also been used. The purpose of the meeting was to help Parentline Plus, an organisation that supports parents and their families, to explore how it might make its services more inclusive of disabled people.

I was not successful in attending or setting up a focus group specifically for Deaf parents and so the consultation draws, with kind permission, upon an informative study recently carried out by Betty Tracey (Tracey 2002) and discussions held with Becki Josiah, DPPi information officer, who set up the Deaf Parenting Project, a distance peer support network for Deaf parents, and helped to produce the video, *Deaf parents: Gaps in Services* (Chowdry 2002). Quotes from Betty Tracey's interviews with Deaf parents interviews are marked at the beginning and end with #.

Nine parents who filled in the questionnaire identified themselves as being black, Asian or mixed race but it did not prove possible to meet with a group of disabled parents from ethnic minorities. The draft report was therefore shared with members

of *Equalities*, a national council of disabled people from black and minority ethnic communities, whose responses were very helpful.

An 'active' sample

The parents involved in DPN's consultation were all involved in national and/or local support networks. As such, they were likely to be amongst those parents with better access to information, resources and support and a reduced sense of isolation. It is important to bear in mind then, that if the parents in *this* consultation said that it had been a struggle to get hold of support, other disabled parents may be finding it even harder. In many ways, however, this was a very valuable group of parents to consult with, since they were well placed to identify the ways in which access to support networks can be helpful in and of themselves and at the same time can facilitate access to other resources.

The size of the sample (overall 150 parents filled in questionnaires and/or were involved in focus groups or individual discussions) means that it is a sizable pool of information out of which distinct patterns emerge, highlighting a number of areas of difficulty and opportunity that need to be more thoroughly explored.

Key findings

Disability and family life

Questionnaire respondents were invited to self-define the experience of disability (see Appendix A, Question Six). Putting the question in this way, rather than asking people to tick a series of boxes relating to specific impairments, gave a much clearer picture of the complexities of disability in relation to family life.

Families are by their very nature in constant and varying degrees of change. One parent might report that they had been disabled since birth whilst another described a condition or illness that was recent in origin. One condition might be stable whilst another changed from time to time.

Parents talked about the relative impact upon family life of different conditions and also talked about impairment in relation to other aspects of family life such as the stage the children had reached, the experience of becoming a single parent, loss of income, whether or not the family had access to services, appropriate housing, equipment and so on. Some of the parents had themselves become disabled as a result of lifting and carrying disabled children. It was striking that a number of the disabled parents who filled in the questionnaire reported (even without being asked directly) that they had at least one disabled child.

Examples were given of where a parent's mental health worsened or improved as a result of a change in the family's social or economic circumstances, the difficulty of getting hold of appropriate support services etc, or else was linked to worsening or improvement in their own or another family member's health. At the same time, a physical impairment can develop as a result of emotional stress.

Disability in its social context

In other words, the experience of disability cannot be seen as a fixed variable but rather as something that is liable to change in both foreseeable and unforeseeable ways in relation to everything that is going on within a family. Partners, and children too, move between different welfare and health categories from time to time, whilst the relative impact of different conditions changes in relation to the changing situations of family members. At the same time, all of this takes place within broader economic and social contexts that can also play a large part in how far parents are able to get hold of any additional resources that are needed.

Needs-led service responses

When it comes to family living, one size quite clearly does not fit all. This was the thinking behind the requirement that needs-based assessment should take individual preferences and all relevant needs into account. And yet in practice it is often regarded as unreasonable if what suits the majority of people is not acceptable to an individual, family or group.

For example, services often appear to be allocated on a formulaic rather than an individual basis - so long for a bath, so long for shopping, so long for cooking, so long for putting a child to bed etc, irrespective of how long that task might take in an individual's experience. In reality this may be affected by cultural or physical considerations or by a mixture of both.

The right to a culturally appropriate service is upheld by equal opportunities legislation, the Children Act and the DDA, but parents' comments indicate that in many cases they did not feel that their expressed needs and preferences had been taken into account.

'In the school they gave the Muslim children ham and pork. They said it's just a few children. I said it doesn't matter how many children it is, it is their right. In fact it was 20 children in a school of 100 children. My son [a boy with learning difficulties] doesn't know what he's eating. He's not going to say anything. But I had told the school. I asked the kitchen staff and they said no-one had told them. '

'I need to oil the hair and skin for myself and my daughter every night. The times they allow are nowhere near long enough. It's the same with shopping. I'm looking for the West Indian foods and at the same time I have to read all the labels to check the foods are suitable for diabetics. It means that shopping takes longer.'

'My son has a Hindu social worker. I asked them to change. She is from Pakistan and they said, she knows your culture. But she is a Hindu and we are Muslim. She is from another culture... '

Service provider issues around the availability of resources and the allocation of available support become mixed in with service responses to the individual. All too easily, the blame for the unavailability of a service can be transferred onto the service user. Parents who express dissatisfaction sometimes report that they feel they are being blamed in one way or another, whether because their demands are seen as excessive or unreasonable or because their expressions of frustration are interpreted as aggressive or depressed behaviour.

'When I started to complain they said I was depressed.'

Deaf parents who use British Sign language similarly find that professionals who are unfamiliar with BSL as a language sometimes make inappropriate judgements about communications involving Deaf parents.

'People who know nothing about BSL see Deaf people as aggressive because BSL involves very emphatic movements and facial expressions.'

Issues around the allocation of resources and availability of appropriate support become mixed in with issues about language and culture.

'For 5 years now I've been trying to get the right equipment to bath my son. Just this week I said, come and see for yourself. I'm the one who does this and I know what's needed. He said, you are not able to explain clearly. I said, then why don't you get an interpreter? In the end he came to my house and saw for himself.

He said, you are right. Now at last, just this week, we have the right bath seat. It shouldn't take 5 years of time and energy.'

Disabled parents' rights and entitlements

'You've got to know your rights and your child's rights. E.g., antenatal class, school etc are obliged to address the access issues. Good thing about DDA is that it gives you a basis for insisting on your rights.'

Many of the parents involved in the consultation were well aware that their own level of knowledge about their rights would not be typical of disabled parents as a whole. Several made the point that whilst they were pleased that Disabled Parents Network is going to produce a handbook for disabled parents, it should not be down to individual parents having to make a huge effort, often at times of family difficulty and often at great personal cost in terms of time and energy, to hunt down scarce information.

Difficulty of finding help when family needs change

'Sometimes you think you have all the information you need but you don't know what's to come.'

Parents report great difficulty in getting hold of information and appropriate support at times of crisis or when family needs change suddenly. Examples given included a sudden worsening of the parent's health, unexpected hospitalisation, death of a partner, a child's health, a social or educational need coming to light, or a change in family circumstances such as unemployment or a partner leaving etc.

It shouldn't be down to luck

'When partner's needs changed and he needed surgery [it was] impossible to get extra help or find out where it might come from.'

'Very difficult. If I had not been a student on a course about domestic violence I would not have known where to go for support.'

'Extremely difficult when I became extremely unwell.'

Part of the problem is the inflexibility within individual services but there is also a lack of liaison between different agencies in respect of meeting disabled parents' support needs. Some of the difficulties arise out of arguments about who should pay, with adult and children's divisions each trying to argue that the cost should be picked up by another division or another agency, such as education or health services. A particularly serious consequence of this is that when adult or child health needs change, changes in support are not readily available.

'Have problems when me or my husband are ill. Continual scare that son could be taken into care.'

'We had to fight to find out even for high medical needs when one or more in hospital [child also disabled].'

'Guidelines needed for professionals re worsening in a parent's health.'

'Changes can happen within hours and circumstances frequently not covered by the 'rules'.'

Part of the problem is the inflexibility *within* individual service provision and partly also the lack of liaison *across* different agencies in" respect of disabled parents' support needs.

'Have epilepsy and MS -no family nearby. A social worker advised if I am 'bad' again -contact police for urgency!'

'Babies change fast, by the time you've solved the problem there is something else.'

'Had to peruse very actively to get hold of it. Nothing was provided for me. Systems too inflexible to cope with fluctuating needs.'

'Ill health always made things harder'.

'Difficult everything takes time although agency staff able to respond immediately – if money is available.'

'Systems are too inflexible to cope with fluctuating needs.'

'No emergency help available from official sources.'

Value of direct payments

Parents' comments on direct payments tend to be very positive. They are seen as putting flexibility into parents' hands, enabling them to set up assistance in the way that best suits family needs, giving a better chance of building up continuity with a team of assistants chosen by the families themselves and enabling parents to make changes as and when needs change.

'Direct payments are fantastic for giving control back to the disabled person but unless there are proper supports for users a parent can feel that they are being set up to fail.'

Parents' comments on direct payments tend to be very positive. They are seen as putting flexibility into parents' hands, enabling them to set up assistance in the way that best suits family needs, giving a better chance of building up continuity with a team of assistants chosen by the families themselves and enabling parents to make changes as and when needs change.

'Having a personal support worker big help when things change suddenly.'

'Getting direct payments for personal care made a huge difference. '

'A friend has social services home care and I'm appalled, direct payments far preferable. '

'Best advice was that I was entitled to direct payments to support my parenting role.'

'Has been v hard to stop social services department intruding. We now have direct payments.'

'Direct payments are fantastic for giving control back to the disabled person but unless there are proper supports for users a parent can feel that they are being set up to fail.'

However, parents who already receive direct payments make it clear that a number of specific and practical issues, for example recruitment, dealing with employment

issues, police checks etc, need to be properly addressed if direct payments are to be used successfully to support parenting. Direct payments user support groups, properly supported by the local authority and able to act in an advisory/administrative role, have a key part to play in this. Parents involved in a user group for people receiving direct payments stressed the need for proper supports to be in place, both for parents and also for social workers.

'It's no good if social services give people direct payments and then wash their hands of them. You need support with employment issues such as national insurance, sick pay, holiday pay, handling and lifting, police checks.'

'A local best value review suggested social workers themselves are not getting the support. They don't feel they know enough about direct payments to feel confident about recommending them.'

Research suggests that access to direct payments varies widely from place to place and indeed between different groups of service users. Only one of the parents with visual impairment mentioned Direct Payments and none of those with learning difficulties.

The setting up of user groups that link in directly with local authority personnel means that difficulties can be addressed as they arise and the learning from individual situations fed back into the system. This moral and practical support can make all the difference to parents' experience of using direct payments.

'The booklet you're given is like weighing through treacle, and the information is not comprehensive. Talking to parents in other places though, they didn't get any support at all.'

When uncommon situations arise it is useful if solutions found in one place can be shared more widely rather than re-inventing the wheel each time a similar problem arises elsewhere. A prospective disabled adoptive parent had to negotiate an apparent "Catch 22" before she could access direct payments.

'Social services weren't initially prepared to think about direct payments package I would need if I were to adopt but adoption service weren't prepared to approve the adoption until they knew how much support I would have. In the end got it on the strength of the potential to adopt.'

A number of specific issues were raised by parents that have to be addressed properly if direct payments are to be used successfully to support parenting. The existence of a direct payments user support group, linked in with the local authority and able to act in an advisory/ administrative role, has a key part to play in resolving such issues. This is a practice that all local authorities should consider.

'There is an issue for parents around police checks because you cannot request one as an individual only as part of an organisation. We're considering getting police checks carried out through the direct payments users support scheme.'

'Fact that local direct payments user group offers a payroll service and advocacy support has been a great help.'

Information needs and the parenting life cycle

Whilst parents have individual information needs, it is clear that the demand for information ebbs and flows in broadly predictable patterns at different stages of the parenting 'life cycle' so to speak. Parents graded their satisfaction with the information they had at different stages, through from when they were themselves teenagers to when their own children were teenagers. This is shown in Table One (see Appendix B).

Maternity services

Whilst disabled parents *demand* for information peaked, as one would expect for most parents, during the immediate ante-natal and post-natal periods, disabled parents' levels of satisfaction with the information available was relatively low throughout pregnancy, birth and the post-natal period, rising slightly during the pre-school period.

Disabled parents' frustration at their restricted access to information and support throughout pre-pregnancy, pregnancy, birth and the post-natal period contains a clear message for the maternity services. Not only is there a need to provide information in accessible formats targeted specifically towards disabled parents but also it is important to take the access requirements of parents with a range of impairments into account when designing and fitting buildings, choosing equipment, planning services and training staff. Only when this is done systematically and routinely is there any chance of meeting needs across the range of disabled parents in a way that does not discriminate against certain groups.

The issue of moral support cannot be separated from the practicalities of information, physical design and organisational planning. A parent who finds that the antenatal unit is the one part of the hospital where disabled access has not been considered is not going to feel that his or her presence is expected and welcomed. By the same token the disabled couple who find that there is someone employed by the maternity hospital specifically to make sure that the unit will be able to meet the specialist requirements of disabled parents will feel correspondingly encouraged.

Feeling discouraged and unwelcome can have a very far-reaching effect on a new or prospective parent's confidence.

Pre-pregnancy

Disabled young people are generally not encouraged to see themselves as prospective parents.

'My life has been profoundly institutionalised. I didn't see parenting as an option for me. I had no sense that support and acceptance would be available.'

'The messages coming to me since I was a baby was, you can't do and you can't be... I never thought that I would be a parent. It meant that when I did get pregnant I had no idea what was going on.'

In addition, information linking specific impairments and maternity issues is very hard to come by. Disabled parents have complex information needs in relation to pregnancy and birth. Not only do they need information about how their particular impairments will be affected by pregnancy, birth and parenthood but in some cases they are also looking for information about whether their impairment and/or medication will have an impact on pregnancy and birth. In reality, rather than having access to both the regular information about pregnancy, birth and parenting, and any additional information needed, disabled parents have less access to information than their non-disabled counterparts.

'There was information about pregnancy etc but NOT about disability.'

'Wish I had known earlier that I could conceive in spite of disability.'

'It shouldn't be down to luck.'

'Rare illness, specific information hard to find.'

'No information available - did ME cause miscarriage? In experience, pregnancy hormones improved ME in 3rd Trimester.'

'No one could or would commit to giving info about how my body would react, as they were afraid it would leave them open to complaints.'

'I was told 'you're fine, go away and forget about it'. Since becoming pregnant it's weakened and closed up the valves.'

Some parents commented that family and older friends had been a useful source of information at this point. Only one person mentioned sex education lessons. A

parent with learning difficulties commented that she had only found out about contraception after she was pregnant

'Sex lessons at school and listening to friends & older people talking.'

'Looking after younger brother and sister's children was a good way of learning. I found I was fascinated by children. I just love them.'

In Betty Tracey's interviews with Deaf mothers, teenagers who had grown up in predominantly Hearing families, that did not use sign language, reported that their access to information via family and friends had been very limited.

#It wasn't til I went to [a boarding school for Deaf children] that I realised other children had Deaf parents Everything seemed so easy for them, they could say anything they like and everyone was involved and together. '#

'Deaf children in hearing families may grow up without access to even basic information. Some will not even have over heard people talking about pregnancy, birth or parenting in family conversations. '

Teenagers growing up in predominantly Deaf families in which everyone uses sign language reported much easier access to information within the family context. However, all Deaf teenagers were likely to have restricted access to parenting education from external sources:

#My parents were there to support me for anything I wanted to know. I didn't go to professional services much, if there was something I wanted to know, I'd read books or ask my parents or my friends. '#

#I could ask anything I wanted and get an answer from my parents. Not like some of my friends who had hearing families, I never felt odd or an outsider. '#

Some felt that there was little information that applied to their particular circumstances as prospective disabled parents. This included fathers, prospective adoptive parents and a mother with visual impairment who needed access to state funded fertility treatment.

'I feel that my access to fertility treatment was affected by prejudice towards disabled people becoming parents.'

'As a father I had very little information at this stage. '

'Not easy to acquire parenting know how. [There are] no parenting classes for adoptive parents. '

A Deaf mother in Betty Tracey's study describes how she took communications with professionals into her own hands during pregnancy.

#'So far as professionals were concerned, yes communication was a bit of a problem, but I'm a good lip-reader. When I was pregnant, I made sure I asked everything I wanted to know, writing questions on paper, back and forth between the doctor and me, so I felt absolutely clear on everything, what was going to happen, what might happen, all the possibilities like Caesareans and whatever, I made the GP write everything down clear. '#

It is important to remember that disabled people also need access to information and support when things do not go according to plan. Indeed the need for information and support at such times is likely to be particularly acute and yet may be easily overlooked.

'Had to have a termination because the baby's kidneys weren't working. There was no information or support.'

Antenatal support/parenting preparation

Roughly half of the parents who filled in questionnaires reported contact with an antenatal teacher. Of these about a third cited them as a good source of information and support whilst between a quarter and a third indicated that they were not happy with the support given.

Parents with visual impairments talked about the issue of access to antenatal classes. One woman commented that she had had to rely on her sighted partner to relay information. Another woman with visual impairment provided a contrasting experience. She was in a small, NCT run class in which she felt there was more time for individual support than in a larger class. This mother had found it useful to be able to feel a model of the baby passing through the pelvic girdle. NCT groups received positive mentions from several parents.

'NCT antenatal teacher kept an eye and came over to help if I got stuck. Small class meant there was more time for individual support than hospital classes. Could feel the body models. '

'Had to rely on sighted partner relaying info in absence of accessible materials.'

'Visual demonstration from the front. Not accessible to people with visual impairment. '

Deaf parents access to ante-natal and parent education classes is often determined by what happens to be available locally. Whilst one individual might be part of a supportive network of Deaf parents another could find themselves cut off from both information and moral support.

#I was lucky, there were several other Deaf mums pregnant at the same time as me, we built a close network, supporting each other.##

Problems that arise in part from the lack of access may be blamed unfairly on parents themselves. A Deaf couple involved in child protection proceedings were told by the courts that they must attend a parenting course. However there were no courses available using BSL. None the less the fact that they had not attended a course was amongst the information used against them in considering whether to take their children away.

Antenatal classes can be useful at many levels; supplying information and practical guidance, increasing confidence and providing reassurance and setting up social contacts that may last well into parenting. And yet some of the parents consulted, most notably parents with learning difficulties; appear to have very limited access to, or even knowledge of, this area of support. This is particularly regrettable given all the evidence that exists about the great value of parenting education for this group of parents.

Wish I'd gone to antenatal classes but I was too scared to go. '

'Very difficult. Most support is aimed at ordinary parents not parents with learning disabilities.'

'You need to know what to expect when you have had a baby. '

'No one told me about no groups'.

The number of references made by DPN members to NCT groups is perhaps a reflection of a historical link between Disabled Parents Network which in its days as *ParentAbility* grew out of the work of the NCT's post-natal support work.

'Local NCT post natal group v[ery] supportive throughout illness, diagnosis, disability.'

'NCT breastfeeding counsellor gave one to one info and support, ante-natal teacher v[ery] g[ood].'

'NCT local branch good. Still in touch with them even though daughter is now 16. I was the only disabled mother. '

Birth and post-natal support

Concerns expressed about access around the time of the birth included physical design of maternity facilities, arrangements for assistance and communication issues.

Discouraging and unwelcoming responses can have a far-reaching effect on a new or prospective parent's confidence. Failure on the part of service providers to routinely assess and address the requirements of disabled parents gives out a message to disabled parents that is no less discouraging and unwelcoming because it is a result of oversight rather than a deliberate snub.

'Many people (professionals and some family) assumed quite wrongly that my pregnancy was accidental. This knocked my confidence. I spent the pregnancy worrying that my child would be put on an at risk register.'

'I wish I had known when I was pregnant/a new mother that DPPi existed I could really have used positive and practical information regarding parenting and visual impairment. I also wish I had known that I didn't have to 'prove' myself as a mother -this would have helped me to enjoy being a new mum. '

By the same token examples were also given of specific information and services, geared to the individual, that helped disabled parents to gain in competence and confidence.

'[social workers] showed me I wasn't a failure just because I did things differently to other mothers. '

'The midwife said, people with disabilities know how to adapt and so they make good parents. '

The issue of moral support cannot be separated from the practicalities of information, physical design and organisational planning. A parent who finds that the antenatal unit is the one part of the hospital where disabled access has not been considered is not going to feel that his or her presence is expected and welcomed. By the same token the disabled couple who find that there is someone employed by the maternity hospital specifically to make sure that the unit will be able to meet the specialist requirements of disabled parents will feel correspondingly encouraged.

How far practical arrangements have been thought through and addressed ahead could make a crucial difference, for better or worse, at the time of the birth.

'Disabled .father's access needs not routinely met by hospital -expected to provide own carer during the birth.'

It shouldn't be down to luck

'PAs [personal assistants} not allowed in one hospital so had to settle for another with bad wheelchair access. '

'Maternity hospital not geared for disabled access (toilets, beds, security system). Did provide a bed with extra room around it in postnatal ward.'

'There were no arrangements for me as a Deaf mother. I could not lip read what the midwife was saying to my nether regions. I had no idea what she was saying.'

Disabled parents' experiences as users of hospitals in relation to their maternity needs (see earlier section), own health and their children's health, is an area of concern already highlighted by calls to disabled parents' help and enquiry lines. The comments made by parents in the consultation related both to physical access and also information needs.

Further research outlining areas of difficulty and highlighting the good practice that is being developed in some places would be very valuable.

'Can get facilitator when you go to hospital for check up. '

The number of respondents who had had contact with consultants was surprisingly high. They were the fourth commonest professional group with whom there had been contact after GPs, Health Visitors and Midwives. Eight parents mentioned that the consultant had been a source of both information and support.

'Consultant gave useful early advice about checking out that the hospital where my wife would give birth would make provision for my needs. '

'Encouraged me to make informed decisions. Very much takes our lead; not at all patronising. '

A number of parents commented on support that had been useful at around the time of the birth. These included moral support and encouragement, provision of technical equipment, and direction to sources of information and peer support.

'Consultant gave useful early advice about checking out that the hospital where my wife would give birth would make provision for my needs. '

'Director of midwives used his contacts to get equipment in and made special arrangements for me to stay in hospital after 2nd birth.'

'The midwife told me about DPPi who told me about DPN.'

It was notable that parents with learning difficulties reported more support at this stage than ante-natally. For some this was really the first point that they received any information or professional input with parenting.

'I was homeless during pregnancy. Just getting enough to eat and keeping warm were the main issues. I stayed in hospital for 28 days after my daughter was born. I was well looked after.'

A mother with ME who had been unhappy about the care she received from the midwife the first time round, employed an independent midwife the second time she gave birth. Since most disabled parents clearly won't be in a position to employ independent midwives or post natal assistants, it is important to consider how this flexibility and willingness to accommodate particular requirements can be introduced into the systems that most disabled parents will use. (See also section relating to the flexibility of care made possible by direct payments.

'If you can afford it, employing private midwife can help with meeting the demands of unusual circumstances. Turned out to be very good value.'

'With hindsight would have insisted on Caesarean.'

'My experiences during first pregnancy/birth helped me make better arrangements 2nd time around.'

Parents with learning difficulties generally reported more support at this stage than ante-natally. For some this was really the first point that they received any information or professional input with regard to parenting.

Two Deaf mothers, interviewed by Betty Tracey, remind us that professionals should try not to make assumptions about the information that a parent will or will not need on the basis of impairment, but should rather respond to the parenting needs identified by the parent:

'Funny it seemed when [had my son, the professionals, HIV, midwife, social worker, everyone thought because he was deaf that I knew everything about how to support him! Any problem he had, any ordinary problem, like eczema rash, they thought I could get support from deaf sources like teacher for the deaf, and so that was not addressed, they only say his deafness and the need to support that! I think that really it's the parent that needs support, not the child. '#

#I really felt that my hearing daughter, she was really 'mine' ... I could bring her up like I wanted, whereas for my son, all the professionals had a piece, I had to go with what they said or thought. '#

Post-natal support

The support of family, friends, and neighbours is important to disabled parents, as it is to others.

'Friend of a friend who is a disabled mother gave me great confidence. '

'Parents with older children gave good information. '

'My mother took over after the baby was born -I was very young - I went back to school.'

'Parents in law were helpful.'

More is said about the value of informal supports based in families and local communities in a later section of this report. However, it should not be overlooked that family and local communities can also be a source of stress, discouragement and unwelcome interference.

'Employing postnatal help provided the flexible care without the emotional complications of a mother/mother in law.'

'I wish my mum had taught me more about looking after my child. Family can be helpful when they are not interfering. '

The post-natal period is a critical time for any parent, and indeed is the point at which several of the parents in the consultation first experienced difficulties with physical or mental health, whilst for others existing problems got worse.

'The first 18 months of my baby's life has been a nightmare for me; until now I feel I just lurched from one crisis to the next.'

'Should have been given help by social services department after my Caesarean; especially as I have other needs to 'Consider i.e. disability.'

'MS developed at this point; wish I had known that more help was available. '

The issue of support becomes correspondingly important at this stage. As at other stages of parenting disabled parents can find themselves on the receiving end of discouraging responses.

'I lost a lot of confidence as a result of people's attitudes towards me as a Deaf parent. I was put under masses of pressure. I'd only just had the baby and already I was being asked, how will you cope when she's a teenager?'

'The baby needed changing and I asked the nurse to pass him to me because I couldn't lift him. She said, 'Get him yourself' as though I was just being lazy. She made me feel really inadequate. '

Others were lucky enough to find good professional support at this crucial stage.

'Health visitor was very sensitive to mine and my baby's needs. '

Effective support for new disabled parents depends upon co-ordination between GPs, midwives, health visitors and specialist health and social services. Co-ordinated, inter-agency response through the antenatal, birth and post-natal period are essential if disabled parents are going to be properly keyed in to mainstream health and family supports in the critical early days of parenting. There is no evidence that this is happening systematically at present though some examples of good joined-up working were given.

Pre-school

Much of the support at this stage of parenting is supplied informally by relatives, neighbours, friends, other parents and local parent support networks. There is also a role for more organised groups that form around shared situations and are run on peer support lines, sometimes with the input of professionals. It is important that all groups of parents, including parents with learning difficulties and those experiencing mental health difficulties, have access to a range of informal and semi-formal supports, as it can make a huge difference to dealing with the issues faced at this stage of parenting; including the often challenging behaviour of small children.

'I didn't know what to expect.'

'Looking after a baby and an older child at the same time was hard. '

'Wish I'd been able to get advice about handling their behaviour earlier. '

'When he was 2 he used to throw things. Very difficult because I was on my own. '

'Community nurse for children helped with behaviour problem. '

'It now helps to know what is wrong with my son [Attention Deficit Disorder] and how to deal with his behaviour. '

Parents with learning difficulties themselves made a strong case for parenting education and support groups

'Kind of information that would be useful is what to do if your child has something in its throat.'

'Crossing Bridges group was very helpful with first aid and other skills that were very useful for parents. '

'Having help from people who stand by you makes parenting easier. '

The level of satisfaction reported with the information available rose during the pre-school period, with marginally more parents saying that felt they had enough information than those who feel that they didn't at this stage (see Table One).

However, access to pre-school group provision, including mother and toddler group was limited or even non-existent for some, including a mother with learning difficulties who had not heard of the existence of groups for new mothers. One mother said that being a parent caused her to see her situation as a visually impaired woman in a new light. At mother and toddler groups it was impossible to make eye contact and she found that other women were often unwilling to initiate conversations. She felt sad that her own marginalisation as a visually impaired parent resulted in the marginalisation of her child.

One parent reported that a full time nursery place was the only help offered by social services. Quite apart from the fact that it was help in the home that the mother wanted, in order to strengthen her own parenting rather than to have the children away from home all day, they were given no choice about which nursery their children could attend.

'The only help we were offered was to take them to a day nursery. But there was no choice. It was this one particular one where disabled children were sent, or if there were concerns about children being abused.'

Comments indicated that access to day nursery places was variable. Whilst one parent was lucky enough to be offered a sponsored place at her local Montessori nursery, another was told that there was not enough room for her wheelchair. On

the whole, however, parents appeared to find their contact with staff in day nurseries both supportive and informative (see Table Two).

'Had access to social services nursery because of child's visual impairment. '

'Being a nursery nurse and registered child minder made it much easier to know where to find information helped to find mother and toddler groups, helpful in meeting other families. ' .

'Used to work in Family Support Centre as a nursery nurse so felt I was contributing. Stepped in in an emergency.'

'Play groups, pre-school groups and nurseries -social services department helped find places as a single father.'

'Montessori nursery gave a free place. '

'I was told, "We don't have room for a wheelchair in our nursery. " ,

The importance of this kind of practical and timely support has been shown by a number of researchers and is all the more important given the concern of the Social Services Inspectorate that parents with learning difficulties are unfairly over-represented in the child protection system. (Goodinge 2000)

Choosing a school

When it came to choosing a suitable school, satisfaction with the amount and usefulness of the information dropped off slightly compared to the pre-school period but remained relatively high compared to the unmet demand for information at the maternity stage (see Table One, Appendix B).

Once again, the parents who felt that they had been able to deal best with this issue, in the absence of readily available information, were those who identified themselves as having been particularly proactive in their approach.

'I went to interview them, told them what support I'd need, I set the meeting up. '

'Went for the one with a good reputation. '

'Had to go out and search couldn't assess schools unless I was shown round properly.'

'Visit prospective schools to find out their attitude to disability. '

Some even had the satisfaction of seeing the situation improve, as a result of their input, in ways that would benefit other parents.

'The school governors' reports now state how the school policies effect disabled people/children re. access and support. '

Access and communication with schools

Although schools' communications and dealings with parents have a direct bearing upon children's educational welfare, a number of parents felt that schools do not necessarily accept that they have a responsibility to facilitate parents' physical access to schools; participation in parents' evenings; letters and messages sent home with children; support with helping children to do homework.

Around half of the respondents had children of school age. Once their children were in school, parents' experience of support was mixed and varied from teacher to teacher even within the same school. Three parents singled out the difference made by supportive head teachers and of governors.

'Head teacher very supportive. '

'Head teacher / governors very good info[rmation] re school's access.'

'Have had to work very hard with schools. '

'Schools need Disability Equality Training. They think they don't have to think about parents because all they have to think about is children.'

Some schools appear not to recognise the links between children's educational welfare and the schools' communications with parents.

'Schools say, "We don't have any disabled parents." What they mean is that they can't see them.'

'Schools see themselves as being there to meet children's needs only and not parents'. They don't see the links.'

Difficulties are caused by the physical inaccessibility of many schools, the inaccessibility of written materials sent out and a lack of awareness that the way in which schools respond to parents can have a very sensitive impact on families.

'I've had to teach the teachers. They didn't make allowance for either my visual impairment or my husband's wheelchair. Our visually impaired

son had to run across the staff car park as they wouldn't allow my husband to drive up to school. I insisted but it took 2 years.'

'In my area most schools are inaccessible to wheelchairs but most teachers are willing to telephone about the children. '

'No help with homework for visually impaired parents.

'It's not just that schools don't send info home in accessible formats. You can't get the face to face contacts either. '

'Any reports written -always provided in print, I took them to the Education dept and told them to blow them up.'

'Secondary school tend to photo reduce. Daughter fills them in or checks what I do. We talked to 1st school about poor quality of copying.'

'Information is not sent home in the right format for me or the children:'

'I got to the school play really early so that I could find a suitable place to sit. At the last minute they said, "You'll have to move. You're a fire risk." It makes me not want to go and see her school plays any more because I don't want her to be embarrassed. '

'When my husband died and when I went totally blind the school said nothing.'

Consultation with parents with learning difficulties who are not living with their children gave an important reminder that parents may have either limited access or else no contact at all to health visitors, their children's doctors', teachers etc once a child has been removed from home. As one mother with learning difficulties, whose children are being fostered by a relative of her ex-partner commented on how terribly cut off from her child this made her feel.

'I desperately want to know how my children are getting on at school but I have no way of finding out.'

An interesting and perhaps unexpected finding was that disabled parents with *disabled* children sometimes, ironically, have better access to information and support in relation to schools and support services than disabled parents with *non-disabled* children. This was illustrated by Deaf parents and those with visual impairments, in particular, who said that the services were far more geared up to supporting disabled children than to assisting Deaf or visually impaired parents to look after their children (disabled or otherwise). However, where there were both

disabled and non-disabled children in the same family, this support was sometimes felt to transfer.

Parenting teenagers

Although relatively few of the respondents had teenaged children, this is a stage where established parents often find themselves facing new information needs and unfamiliar challenges. This was reflected in the ratio of good to poor information, which dropped to levels around the unsatisfactory ones reported in connection with the maternity period (see Table One, Appendix B).

One parent was concerned about the negative consequences for her children of having to take on too much work in the home, because of the lack of services provided to her as a disabled adult.

The few parents who mentioned that their children had been involved in 'young carers' projects felt on balance that these had had a positive role to play in terms of offering recreational opportunities for families and peer support opportunities for young people themselves. Nonetheless, reservations were expressed about the use of the term 'young carer'.

'The local Young Carer's group has been a godsend for my children. I don't like the name but the group is invaluable for peer support and for individual support for the girls when times have been tough like when their father walked out. They really appreciate having somewhere to go where they don't get bullied because of my impairment (all the kids at Young Carers have a disabled person in the family) and the Young Carers youth worker is a nice safe person for them to talk to when they need to. She understands that having a disabled Mum can be difficult and the girls know that she won't tell me what they've been talking about unless they ask her to. '

'Young Carers' group: support for children [and] family outings organised with support. '

'Young Carers' worker provided help with learning to read for sighted child. '

'Young Carers' support ended when primary care worker moved on. '

'Nominating your child as your carer means quicker access to adaptations & equipment.'

'Help was better before I became wheel chair bound. Discrimination from professionals and very little help so that it has fallen to two youngest children to help and they have needed counselling as a result.'

Although relatively few of the respondents had teenaged children, this is a stage where established parents find themselves facing new information needs and unfamiliar challenges. This was reflected in the ratio of good to poor information, which dropped to levels around the unsatisfactory ones reported in connection with the maternity period (See Table One, Appendix B).

A disabled parent with a disabled child spoke about the difficulty of getting hold of information related to her disabled child's 'transition' to using adult services. She found that this was made even more complicated by the fact that this term means something slightly different in the jargon of education, health, social services, the police, and the government sponsored 'Connections' project that deals with the move from school to work.

'Really hard to find information. I wrote to social services department and health service to ask them for their transition policy which they are required by law to have.'

'Teenagers are hard to parent because they have tantrums just like 2 year olds but they're so much bigger!'

'Very difficult and frustrating.'

There were also encouraging instances where parents of teenagers found useful resources, often from informal supports in the community but sometimes through more formal channels. The mother quoted above, who had an adolescent son who is also disabled, said that she resorted to a technique she has used before when desperate for more information and put a notice in the paper to find other parents in the same situation to meet up with.

'I put an ad in the paper and formed a support group.'

'As a single father, didn't feel I knew enough about girls. Daughter 9 years old when she started her periods. Had to get the woman next door to explain to her what was going on. '

'My daughter started her period then missed a few - I didn't expect this but my mum told me it was normal.'

'Helped that I ran a boys club and a youth club for a number of years. '

Relationship with professionals

The questionnaire responses suggest that many parents somewhere along the line are lucky enough to find a professional who gives them support, information and encouragement. As in earlier studies (Wates 1997; Olsen and Clarke, 2003), the picture is extremely mixed. Any one of a range of professionals including family doctors, midwives, health visitors, occupational therapists, social workers or teachers may be picked out by one parent as having given excellent information, moral support and useful referrals to other sources of help; whilst another parent will mention the same professional group as having been unhelpful. A number of parents indicated that their experience had varied from one encounter to another within the same professional group (see Table Two, Appendix B).

Health visitors, occupational therapists, physiotherapists and mental health counsellors all receive more 'positive mentions' than might have been anticipated from the number of parents who had had contact, whilst consultants, children's social workers, housing officers, educational psychologists and respite care facilities are all lower down the ranking than might be expected taking the numbers who had had contact into account (see Table Two, Appendix B).

There were a small number of professional groups in relation to which more parents ticked 'not happy with support given' than against the total of 'positives' checked for that group. However, as the contact figures were in each of these cases relatively small, it would be unwise to make generalisations. At the least however these findings, taken together with parents' comments, would suggest the need to discuss these areas of service provision at greater depth and with larger numbers of disabled parents to see whether these findings are borne out and, if so, what could be done to improve the support given to disabled parents.

Alongside these individual variations, of considerable importance in the lives of the individuals and families concerned, distinct patterns of response emerged in relation to different professional groups.

Social services

Two thirds of the parents who filled in questionnaires reported having contact with social services. In most cases this involved contact with both adults and children's services though 22 parents reported contact only with *adult* services, and 15 only with *children's* services. In the case of adult workers there were indications of a huge variation in practice. It was not that adult social workers received few positive commendations for good support, referral and information (indeed, 9 parents indicated that they received all three from this one source), but that they received a disproportionately high number of ticks under 'bad support'. In the case of children

social workers from Children & Family services a low total of positive mentions was accompanied by a high number of negative mentions; reflecting a more consistent picture of dissatisfaction (see Table Two, Appendix B).

These figures are amplified by a large volume of strongly worded comments indicating the strength of feeling amongst disabled parents about social services departments.

'Need a chapter on how to be careful of social services, They discriminate if one is vulnerable.'

'Don't even mention these people.'

'There is no point in asking social services to assist in parenting. '

Specific comments indicate that disabled parents feel that social service systems and structures are more geared up to child protection than family support; being quicker to intervene in ways that potentially undermine the parents' role than to come forward with the specific support that parents are seeking.

'Social services treat children of disabled parents as "children in need" - and have so much power!'

'Help is centred on children rather than parents. '

'Social services slow to support, quick to intervene.'

'Has been v hard to stop social services department intruding. '

Parents spoke of the lack of liaison between adult services and children's sections and between social services and other agencies such as education and health. Some of the difficulties arise out of arguments about who should pay, with adult and children's divisions each arguing that the cost should be picked up by another division or another agency, such as education or health services

'Parenting is assessed without taking disability into account. '

'Disability is assessed without taking parenting into account. '

'[Adult services] wanted to share the cost with ILF, then they thought that they would share the cost with children's services and that caused real problems because then you have to have an assessment on your child ... they write a report mainly around all the negative aspects of what you can't do with your child ... It means everything starts to get divided up in

B very artificial way. "... is this help for the mother to look after the child or is it for the child?". "Is this for your care needs or for the child's?"

'Husband in wheelchair, mother and children visually impaired. Really wasn't clear which social services division to apply to. '

One consequence of this lack of clarity is that at the point that adult or children's health needs change and support is urgently needed, changes in support are not readily available.

'When son was diagnosed at 17 months (juvenile arthritis) social services department told me we fell between adult disability and child disability.'

Another concern was the lack of information about what support is available and how to go about finding it.

'Had a good social worker but she left. Nobody told me where she went. Don't know how to get another one.'

'Extracting help from social services has been a nightmare. '

'Adult disability service useful so long as you know what you're looking for. You have to have knowledge before you can get the knowledge.'

'System of having cases "banked" rather than active makes new contact very impersonal.'

Even help that has been put in place does not necessarily feel secure. Reviews of care levels initiated by social services departments rather than by parents and constant changes in personnel amongst both social workers and care agency staff, can leave parents feeling that they don't have enough control.

'I have had 7 [adult social workers] in two yrs. Support has varied, social services department constantly say that maximum they will give me is 8 hrs a day. Constant uphill struggle to maintain the help] need. '

'... every day you receive so many hours care, from a different person each day. [The care agency] send someone that's probably just out of college a lot of the time, to help you look after a baby... and you don't have a lot of control over this you really don't. '

'My daughter had 29 professionals in her life!'

There is a strong awareness amongst disabled parents that social services departments have the power to remove children from home. The parents who filled

in the questionnaire to whom this had actually happened were all parents with learning difficulties. This is consistent with 551 findings about the unjustified over-representation of parents with learning difficulties in child protection proceedings (Gooding 2000).

'Whole families are affected by the authorities attitude to parents with learning difficulties. Nephew's baby taken away at birth. He's a really gentle person he was looking forward to being a dad. He would be a really good dad. But his mother had a child taken away and his aunt and the authorities gave him no chance before stepping in. '

'They threaten you with a care order unless you do what they say but then they do it anyway. Then they can control how much contact you can have.'

'I wish I had known not to involve social services because they took my child away from me and placed for adoption against my will. '

Fear of having children removed from home was also mentioned by other parents as a cause of anxiety and a deterrent that would influence their readiness to approach social services for help. A single father spoke of the need for social services departments to address their off-putting reputation.

'Social services put the fear of Christ in everyone. You were always on your guard. Single parents particularly afraid of having children taken away. I told the social services department, "You have to educate people that you're there to help them. Have to reckon with your past reputation and take steps to overcome it."

Having some means of establishing good communication with social services departments was seen as important.

'Being a social worker myself I know who to ask. '

'Advocacy Service helped with problems with social services department.'

'User advocacy groups can help negotiate with social services about children being taken into care.'

There were a number of instances of supportive practice and useful referrals from social workers.

'Positive attitude of social worker in securing direct payments for me to care for my child when my wife returned to work.'

'Learning disability support team was helpful.'

'Wish I had known earlier that they could support provided child minding.'

'Referred to local parents' group & Independent Living scheme.'

'You don't have to struggle on your own -SSPD (local disabled parents' support organisation) and kids section of social services.'

More comments were made about social services than in relation to any other professional group. It was notable that the majority of the relatively small number of positive comments related to parents' satisfaction with direct payments. The importance of this issue was reflected in one parent's words,

'if I had known the only way to get Direct Payments was to move authorities I would have moved a lot sooner.'

Health visitors

As the single support service provided to all parents on a statutory basis between birth and school age, health visitors were, not surprisingly, mentioned by the majority of parents (102 out of 120). Judging from the questionnaire responses (see Table Three, Appendix B) many health visitors play a crucial role in providing support, helping parents to get hold of information and linking them to other sources of support. It is interesting to look at the columns that show where more than one type of help came from the same source. Health visitors again came at the top of the list, with occupational therapists and adult social workers in next.

The range of roles attributed to health visitors was wide ranging, including providing moral support to a prospective adoptive parent, linking a mother with learning difficulties who was depressed, with a personal supporter; pushing for a mother to be allocated home help by social services and helping the child of a visually impaired parent with homework.

What parents valued was an ability to work flexibly and supportively, backing them to find their own way of doing things.

'Health visitor has been great and hasn't once asked, how are you coping?'

The generally high levels of commendation make instances of unsupportive practice stand out. A mother with learning difficulties, who was living in a B&B at the time, felt that the health visitor was always very critical. Another mother felt that the critical attitude assumed by the health visitor got in the way of her support.

'Health visitor asked inappropriate/undermining questions regarding my visual impairment in the early days of parenting. I brought my mother as a personal supporter to support me challenge the blatant prejudice expressed by the health visitor about my capabilities as a mother.'

'Health visitor was telling me things to do that I knew would not work with visually impaired child.'

'The health visitor seemed to assume that because I was middle class and well educated there was no problem. The fact is that she failed to pick up that breast-feeding had failed due to fatigue and the baby wasn't thriving. The problem was made worse because the post-natal clinic wasn't accessible so she visited me at home and the baby didn't get weighed so often.'

One mother indicated that she saw the flow of information between herself and the health visitors as two-way.

'Both health visitors were exceptionally good. However they had little information available to them -I have given them info about how I overcame difficulties so they can help other disabled parents.'

GPs surgeries and joined up working

GP's surgeries are in many places increasingly versatile in terms of the ways in which they offer support to families so that the relationship with an individual GP is only one aspect of this service. One parent specified that the GP *care advisor* was the most useful professional, another that they had looked to the *practice nurse* for support more than the GP, another that they had very good support from the *local doctor's school nurse*.

One mother had received information, referral and support from the nursery nurse based at the local surgery. Another said that she talked with a counsellor attached to the GP's practice about anxieties in relation to her teenage daughter's eating disorder. Some respondents recognised the role of GPs in facilitating access to other resources. A GP who chooses to take on this role may also be proactive in initiating inter-agency co-ordination to support families in which one or both parents are disabled. One example of joint working is the 'WellFamily Projects' currently being developed in some GP surgeries (Clarke et al 2001).

'Anyone planning a family must make sure their GP and other medical carers are fully supportive and, if not, find someone who is.'

'If the doctor's someone you can talk to it can be very helpful.'

'GP has helped when needs changed.'

Mainstream, not 'special'

'We wanted help to be mainstream not "special".'

'We held back from asking for help because we didn't want to get services involved and give out the message that we couldn't cope.'

Disabled parents' satisfaction with services tended to be higher in relation to 'universal' services based in health and education, than in relation to specialist services, whether these were based in health, social services or education (see Table Two, Appendix B).

Sources of information and support accessed through primary health care and mainstream avenues of parent and family support are generally more acceptable to parents precisely because they are the services that all parents use. Many parents are hesitant to approach social services in case this is seen as a sign that they are not coping. This is reflected in parents' comments about preferring their needs to be met within the mainstream alongside other parents and families.

However, this underlines the problem, discussed at various points in this report, of a general failure within mainstream primary health care parent and family support to ensure that services, information and sign posting to specialist sources of support are systematically provided for disabled parents.

The consultation findings highlight the need for joined up work across agencies, to create accessible and non-stigmatising 'points of entry' to both mainstream and specialist services to support disabled adults with parenting.

Practical supports

The extent to which the practical support needs of parents and children are met is clearly crucial to children's welfare. Parents struggling to prepare meals in housing not properly adapted to suit their physical needs; without access to the basic range of equipment needed for looking after a dependent child; stranded at home with no means of getting out to do the shopping or take the children to play in the park; struggling to meet the emotional and developmental needs of children whilst waiting up to two years themselves for a counselling appointment; unable to read

any of the letters that come back from school because they are in small print: will all be disadvantaged in carrying out their parenting role.

The consultation provided useful and specific information about the areas of practical difficulty facing disabled parents and at the same time provided useful pointers to sources of potential support. These are explored below whilst areas for further research have been highlighted in the final section of this report.

Housing

'Appropriate housing is absolutely essential.'

Given the fundamental importance of housing to family welfare, it was a disturbing finding that three times as many parents reported that they were unhappy with their dealings with housing officers (see Table Two, Appendix B) as those who reported positive contacts. The contact base in this instance is too small for generalisations to be made but all the same these figures suggest a pressing need for further research.

Parents' comments suggested that it is not only the type of housing available that can be an issue but also *where* the housing is located and also the *timing* of support. Access to housing adaptations is accessed in many places via Community Care referrals and care plans. Support from a range of professionals, in particular occupational therapists but also consultants, social workers, GPs etc, appears to be key to disabled parents' success with re-housing and access to major adaptations.

'They have their books. They don't see you as an individual. As a single parent they want to put you in a certain area.'

'I didn't want to live in any of the places offered.'

'A catch-22 situation. Adoption didn't want to give me a child till I was in an accessible house; housing didn't want to give me a house until I had a child.'

'Our housing needs only picked up because of disabled children's needs.'

Access to adaptations and physical therapy

'By the time you've not solved the problem there is something else come up.'

The consultation findings suggest a bewildering number of routes through which parents may access occupational therapy and/or physiotherapy services: through social services, hospitals, rehabilitation units or health-funded community based teams. In addition some had consulted independent professionals.

The majority of parents who had encountered occupational therapists had done so through social services, as part of the Community Care assessment process. However it has been shown elsewhere that assessment procedures do not routinely cover parenting tasks whilst the process of review may not take into account the changing nature of parental requirements as children develop (Goodinge 2000, Wates 2002). The link with assessment can also mean that the interaction with the occupational therapist becomes mixed in with ongoing arguments about cost centres and the availability of resources. The dual role of social services departments relating to both support and scrutiny may further complicate the issue and make the service less acceptable to parents.

'The OT has not done an assessment independently. She said she has gone by what the social worker said.'

'Not happy with social services QT; good support from independent QT.'

'I prefer Community OT -useful because you can self refer and you don't have to go through social services gate-keeping process.'

It was clear that occupational therapists are felt to have the potential to unlock important resources for parents (in particular those with physical impairments) in terms of adaptations to housing and access to specialised equipment to help with parenting tasks.

'Very good support. Mainly because she was great person. 'OT very helpful following surgery.'

'Assessment Centre in Oxford assisted me in finding my own solutions - very empowering.'

'Grants available from social services departments.'

However there were numerous comments about the length of waiting times, shortage of resources and the fact that occupational therapists do not appear to be routinely trained and equipped in relation to the parenting support needs of disabled adults. What is potentially a key resource for disabled parents, all too often becomes a source of frustration, delay and confusion, with little consistency across local authorities.

'Push for OT assessment, try to cover everything, difficult to get re-assessment.'

'Have got to wait 3 years for an appointment. 'Slow. Tell them as soon as possible.'

'As a single parent with a disabled adult son age 25 and many health problems of my own and no family in England it is extremely difficult. '

'Everything takes time, social worker say. How much time? It's 12 years now.'

Equipment

There are very few specially designed items on the market such as the pushchair designed to fit on to a wheelchair. One solution is to find out about a mainstream product that other parents in a similar situation have found useful. Sometimes designs that start out as one-off designs for individual parents are later found useful by large enough numbers to warrant production. DPPi information service was seen as a useful source of information on all of these options, whilst both REMAP and the Repetitive Strain Injury Association have been approached by individuals for help in creating one-off solutions.

'REMAP If equipment can't readily be found they are good source to contact for adaptations. '

'Found child hip seat in a pregnancy magazine. 'Adapted cot was very useful.'

.Wish I had known earlier that a playpen would have been invaluable. '

'Useful info about equipment came from DPN and DPPi also REMAP.'

'So difficult to get info that most of the time I gave up and got by or else had to fight really hard to get what I needed.'

'Filling bottles v[ery] difficult with visual impairment. Husband came up with some good ideas.'

'You couldn't get hold of push chairs, high chairs or special equipment. '

'No baby carrier/pushchair to fit wheelchair.'

'Useful advice on choosing nursery equipment from ParentAbility mothers. '

'Repetitive Strain Injury Assoc built equipment to my design and needs.'

'I go shopping little and often so that the bags aren't so heavy. '

A more detailed piece of work would certainly be useful to highlight disabled parents' perceptions and experiences of getting hold of equipment, adaptations and physical therapy. This is an example of where the relevant professional body could have an important role to play in encouraging more consistently good practice. The College of Occupational Therapists might, for example, provide an overarching guide to including disabled parents in training and set up a special interest group to look at how well occupational therapy departments are doing in relation to the recommendations made in *A Jigsaw of Services*.

Holidays

Holidays present challenges both in terms of finding accessible places to go away as a family but also in terms of support with school holiday activities for families remaining at home. The information needed is therefore both national and local.

'Really difficult to get information about accessible holidays.'

'Always look for a special needs help form, but the form often says in small print that it can't be guaranteed.'

'Also see DialAbility for information on accessible holidays.'

'Hard to find information on school holiday activities and support.'

Finance

Whilst the questionnaire did not ask about respondents income levels a number of parents did identify serious financial concerns and the impact of these both upon practical parenting and their personal levels of stress.

'Lack of money makes parenting harder.'

'Poverty is the hardest thing.'

'Uniforms, shoes and trips are all expensive.'

'With free school meals meant they got a healthier diet than they would have. Relied on 2nd hand. Children are bigger these days and wear adult clothes earlier. A friend who is a butcher used to give us bones.'

'Challenged DSS when they cut my benefits after therapeutic earnings rule. They have no idea of the distress and panic caused to a responsible honest parent.'

It was pointed out by a number of parents that there is no benefit applicable to disabled parents. Assessments for disability related benefits do not consider parenting tasks and responsibilities, whilst benefits for parents and families do not take into account the additional costs of being a disabled parent.

'No benefit applicable to parenting.'

A single disabled parent pointed out that when he went onto sickness benefit he became ineligible for family income support; a situation that he considered was bound to discriminate against disabled parents who have been the sole family breadwinners.

'Worse off "on the sick" because you don't get income support. Works against parents who are ill or disabled.'

Some parents had found useful sources of information and support, including debt advice, from a CAB office and support with welfare rights from an advocacy information service, others had struggled to find help.

'Advocacy Information Fdn (Cleveland) welfare rights - filled in all the forms, were at the end of the phone and made house calls.'

'Took a lot of effort.'

'Word of mouth only.'

'There was still more I didn't find out about straight away. Some are more helpful than others.'

'CAB led to debt advice with legal aid.'

Poverty causes serious problems for many disabled parents. One parent however identified another difficulty in that services to adults are charged whilst those to support children are not. This means that access to a range of services that might be of value to support disabled adults with parenting are cut off by means testing.

'Services only any use if you're penniless.'

'A number of parents identified financial areas that they felt should be covered by the handbook.'

'Clear pointers needed re financial support or financial benefits to help with parenting.'

'Get someone to write a short section on pension rights.'

Prioritising access to services that support parenting

Any Community Care services with a direct bearing on a disabled adult's parenting tasks and roles should be routinely included in assessments (DH 2002a & b). By the same token, access to services, adaptations and equipment that will assist disabled adults to carry out their parenting responsibilities should be prioritised, since this is in the best interests of children.

Counselling and support with mental health

It is misleading to separate out the issue of mental health support as if it only applies to certain parents. All parents are affected by stressful events, which of course can be long or short term, a result of predictable triggers or else a response to totally unexpected events. Access to a wide range of mental health supports should be readily available to families that contain disabled members, as to any others. Once again, it is reasonable to argue that the access of adults with parenting responsibilities to counselling services should be prioritised in the interests of children.

A relatively low number of parents report contact with a mental health counsellor. None the less the support appears to be valued by most of the parents who have been able to access it. Along with health visitors, mental health counsellors are the only groups of professionals where the number of total positive mentions is greater than the numbers who have had contact (see Table Two, Appendix B).

'Very helpful to gain focus.'

'Adult psychological Dept helped me come to terms with my disability and take back power for my own life.'

Where parents have serious and or long-term mental health difficulties it was felt that assessments and service responses rarely take account of parenting needs, or else focus on scrutinising capacity rather than on providing support. Frustration was expressed that a higher priority isn't given to locally based, mental health family projects as these were felt to offer continuity of support in a way that parents find approachable and supportive.

Legal and advocacy issues

Advocacy

Personal advocates can have an important role to play in helping disabled parents to negotiate with services in complex and sensitive areas, especially where child protection is being raised as an issue.

'You need a friend who is a psychologist or counsellor who can speak up for you as a parent. '

'Advocacy service gathered information, supported my daughter so that professionals had to listen to her. '

They are often in a good position to advise on matters such as benefits or legislation, follow through on complaints and engage with the legal system.

'Volunteer advocate helped me understand the legal issues.'

'Advocacy Service - helped with problems with social services department.'

'User advocacy groups in respect of negotiating with social services about children being taken into care. '

'Contacted DPN for help making a complaint.'

Making contact with advocates in the first place is often a matter of luck since the majority are in the voluntary sector. The question as to how parents found advocates received wide-ranging answers from 'word of mouth', via local disability or welfare support organisations through to direction by the courts. Some social services departments appear to be better than others at linking parents up with advocacy services in the voluntary sector.

'I haven't needed them myself but have given other parents contact numbers. '

'Independent Living Advocacy.'

'Advocate at ME centre.'

'Using advocates from Scope and DPN.'

'Got personal supporter through health visitor.'

'Became aware of local advocacy grip through local direct payment support group.'

'Found through word of mouth.'

'Advocacy not available.'

'Professionals recommended finding an advocate because of problems with social services department.'

'Handbook should identify local sources of advocacy.'

Legal information and support

A number of parents reported that it had been difficult, and for some had even proved impossible, to find legal information and support.

'I have needed legal support for over twenty years still on going and I haven't found it yet.'

'Difficulty finding solicitor to take case.'

'Couldn't get legal advice from CAB.'

The contact with legal services was not always found helpful.

'Got hold of legal support from my mum. It wasn't helpful.'

'Found legal services "tough", received bad advice.'

'My husband knew how to make an appointment. Solicitor was not helpful. Did not explain things well to us.'

The ways in which parents had contacted lawyers were very varied; sometimes making contact through advocacy services or personal supporters, sometimes through word of mouth recommendations, and sometimes quite simply by way of the Yellow Pages or a newspaper advertisement.

'Legal advice through contacts in the Disability movement.'

'Solicitor helpful, [found through) court welfare officer.'

'Social worker put me in touch with a solicitor who was useful.'

'Found through phone book and word of mouth. Found solicitor through newspaper advert.'

Parents value advocates and lawyers who are able and willing to work with both Community Care and children's legislation to uphold disabled parents' entitlement to support, defending parents who felt that they had been discriminated against, and explaining legal matters clearly to parents.

'Took legal advice about an access/abuse problem. '

'Went twice to the solicitor. No results yet but haven't given up.

'Found a firm that specialises in Community Care. '

'A lawyer in the old Kent Road specialises in custody cases I took legal advice on the children's statements. The letterhead made them sit up and take notice.'

Disputes about custody

The point was raised by a number of parents in relation to disputes over custody that deliberations and decisions of the court may unwittingly discriminate against disabled parents.

Some parents, notably a mother from a same sexed couple, and a single father felt that they were facing a double discrimination. The issue for the lesbian mother was that 'residency rights' are only granted to one mother in a lesbian couple, and

'disabled people tend not to be treated well by the courts', she had no assurance that the situation would be dealt with fairly by the courts if, for example, her partner were to die.'

A woman with an invisible impairment who is an intermittent wheel chair user also felt that false assumptions were sometimes deliberately fostered by lawyers, the solicitor said in court, 'I've seen her on a bus'. Two parents, one a mother and the other a father and both with physical impairments felt that their access to their children had been unfairly restricted by decisions of the divorce courts on the grounds of impairment.

A mother who contested custody with an ex-partner (non-disabled) who had been violent toward her and the children was concerned at the attitude of the court mediators. She felt that they had been more judgemental in relation to her disability than in relation to his violent behaviour.

These instances suggest that the courts may be failing to challenge prejudicial judgements and assertions being made in relation to disabled parents. A similar conclusion was reached on the basis of research into custodial decisions by the courts of New South Wales, Australia [McConnell and Llewlyn 2001].

'Went to crown court as adoption was contested. '

'Handled my own court appearance in connection with custody. '

'It was as though because I was disabled the normal questions [in relation to the behaviour of violent ex-partner] were not asked.'

'The courts chose to give custody to me, even though I wasn't the child's biological father, on the grounds of my ex-partner's violent behaviour. '
[Disabled father]

'Needed legal help at the time of his divorce. Court welfare officer contested custody for her son who had another biological father. However custody was awarded to interviewee because the wife had mistreated her son. '

'The first lawyer was just agreeing with the social workers. Second one is supporting me to get unsupervised contact with 15 yr old daughter. '

A mother with learning difficulties and a mild physical impairment had been involved in producing support materials for parents with learning difficulties and also helped to organise a conference on the subject. She was devastated that her children were still removed from home and sent to live with a relative of her ex-husband.

Complaints

Just over a third of the parents (42 out of the 120 who filled in the questionnaire) said that they had made a complaint at some stage although the majority of these were of an informal nature rather than formal.

Some parents strongly advised others to persevere in speaking up for themselves if they were not happy with the way they were being treated, and pointed out that they would potentially be helping all parents in similar situation through their persistence.

'Formal complaint through council's complaints officer. Not only helped me but hopefully has improved the situation for all parents in my area. '

'Only verbally. I keep going until something changes. I don't go away.'

'Would go straight to head of department.'

'Complain. Don't take no for an answer. Be persistent.'

A few parents said that they would have liked to have made complaints but either had not had the energy to do so or else ill health had prevented them.

'Hadh't the time or energy.'

'Some parents have not the support to "fight".'

'I have many, many complaints to be made. Because of my health I have not been able to do much about numerous complaints.'

Others had very mixed feelings about the consequences of seeking to complain. Of those who said that they had complained only 18 felt that the situation had improved as a result whilst 15 considered that the situation had got worse since (and in some cases as a result of) making the complaint.

'Against a solicitor - she was dismissed from her job. '

'To councillor and MP re access to schools, some improvement. '

'Fractionally better following verbal complaint. '

It shouldn't be down to luck

'Involved local councillor as social services kept passing the buck - complaint forced a decision.'

'Complaint through health visitor and she called Community Support team together.'

'Approached individual diplomatically, result satisfactory.'

'Formal complaint against social services upheld. Other complaints "disappeared". Went to High Court judicial review. '

'DPN co-ordinator is helping me to write a letter of complaint to social services department, head of dept. '

'Things seem to be improving slowly.'

'Complaint made matters worse.'

'Complaints have gone to review panel stage with County Council -I still have no service. '

'Now have no GP as surgery rotated doctors as I had complained. '

'About home helps, made situation worse. Informal complaint through a colleague of theirs. '

'I have learnt never to complain as things only get worse! Even with advocates helping. '

A number of parents described the outcomes of the complaints as mixed either in terms of the difficulty of the process or else in terms of the outcomes.

'Results mixed: Health visitor directly when my son was 4 weeks old. Although it was an emotionally difficult to undertake health visitor's attitude towards me did improve. Although I have since moved I have a deep mistrust of health visitors and feel reluctant to express any difficulties to present health visitor.'

'Local councillor helped get parking at school, this upset school. '

'Made a formal complaint to social services department but heard nothing more. Has asked solicitor to follow it up. '

'I went through a long and involved complaints procedure with social services department because of way I was treated and indeed lied to. After some months of letter writing I had a meeting with social services directors who all agreed that I had been misled, my case had been wrongly dealt with, social worker had given me wrong info and had not carried assessment out properly. They told me they were reviewing practice and would use my case as one of a few when considering changes. I didn't quite believe this. I do now have a care assistant on weekday mornings. Feel this is more to do with causing a fuss than anything else.'

One parent went successfully through the formal complaint procedure only to find herself subjected to moral pressure not to pursue the service.

'The OT said, the court order means that you've queue jumped. Do you really need it?'

Once again, this was an area of the questionnaire that threw up some encouraging and some disturbing results, suggesting that further research in this area would be valuable.

Community supports

Parents find information and support from a wide range of support organisations in the non-governmental sector. Between them, respondents mentioned eighty-five different voluntary organisations Their positive feedback suggests that disabled parents find organisations in the voluntary sector approachable and responsive to

individual situations. The usefulness of telephone help-lines was mentioned by several parents.

A developing area of parent and family support is the growth of parenting education and support groups for parents. A number of parents mentioned such initiatives, which are often run by non-governmental organisations. An encouragingly wide range of groups was mentioned including groups for parents of disabled children, fathers' groups, a parenting group for parents with learning difficulties run by a clinical psychologist and a community nurse, a group for parents with mental health difficulties and a group for parents with drug and alcohol related problems.

It is not always possible to tell if the support, information etc was provided by the national organisation or a local support branch since many organisations function at both levels. Nonetheless the value of local sources of personal contact and support was highlighted by parents.

It is interesting to see just how varied the forms that community supports take are. Parents mentioned receiving support from a local MP, local councillors, a student community action project that undertook gardening and decorating, etc.

A developing area of parent and family support is the growth of parenting education and support groups for established parents. A number of parents mentioned such initiatives, which are often run by non-governmental organizations. An encouragingly wide range of groups was mentioned including groups for parents of disabled children, fathers' groups, a parenting group for parents with learning difficulties run by a clinical psychologist and a community nurse, a group for parents with mental health difficulties started by Springboard and a group for parents with drug and alcohol related problems.

'People come into the group through personal contact, word of mouth.'

'Child Psychology service "positive parents group".'

'Mothers' Union run parenting courses using the Family Caring Trust material.'

'Parenting skills course (Parenting Matters) I was on the Equal Opps steering group for a while.'

'Parenting skills course taught me to pay good attention to my son's needs and my own.'

'Antenatal/postnatal yoga class.'

Disabled parents may value the opportunity to meet with others dealing with similar situations and where there are several disabled parents in a neighbourhood they may welcome the opportunity to form a support group. However, it is important that disabled parents do not feel that they have been *sidelined* in relation to mainstream parent education and support. All ante and postnatal clinics, parent support groups and primary health care facilities should be easily accessible to parents with a range of conditions and impairments.

'If it's parenting education they're talking about or parenting support it should be available via mainstream.'

Roughly a fifth of respondents mentioned that they belonged to local groups that could broadly be described as 'peer support'. These included at least six general disabled parents groups, a group for parents with visual impairments and two others for parents with learning difficulties, an advocacy support group, a Direct Payment users' group, a group attached to a family mental health project, a Family Centre for black families and an e-mail support network for people with ME. Another group had started out as a group for parents of children with learning difficulties but had grown organically to include friends, in laws and the beginning of the next generation as the original children and their siblings grew up and started to produce families of their own.

Because of the organic nature of their formation and development, local groups tend to be fluid both in terms of their composition and goals, changing from time to time as children pass through different stages, as the health and availability of member changes and in response to available funding. A group for mothers and toddlers may become in due course a group supporting parents of teenagers or even an intergenerational group for grandparents and new mothers. What starts out as a peer support group may over become time oriented towards consciousness raising and/or passing on information to new parents.

Local groups are often resistant to the attempts of funders and overseeing organisations to 'drive' them. Recognising this DPN, a national disabled parents' organisation to whom several local parent support groups are loosely affiliated, has a policy of promoting the independence of local groups to form their own identity, funding base, goals and structures.

Concerns for financial security and future viability tend to be a feature of most community groups at this time, even though the funding levels of those mentioned and spoken with as part of this study varied hugely; from a group that had made several successful lottery bids collectively totalling into six figures, through to the group that kept its weekly contributions from members in a tin.

Family and friends

Family members can be seen as an invaluable source of moral support, information and practical assistance. The help of parents and friends is often particularly useful in emergency and crisis situations.

'Over the years you develop a network that can be drawn on in an emergency. Networks are really, really important.'

'My mother is main help -she talks to the professionals and then explains to me as I have difficulty understanding them.'

'My mum best help and advice.'

'Help from family members made parenting easier.'

'Friend of a friend, who is a disabled mother, gave me great confidence.'

'Friends' mother for information and support. I rely on friends for shopping.'

'Moral support of friends and disability networks is essential.'

'The greatest help is from a next human.'

At the same time, a range of comments on welcome and unwelcome interventions from family shows how important it is that neither statutory services, nor for that matter the voluntary sector, should make assumptions either about the availability of family support or about its acceptability to parents as the main, or in some cases the only, source of support.

'Worrying assumptions very often made about partners (especially itself employed/ working at home) being in a position to step in and help as they are on hand.'

'My mother & father offered to help when I became a single parent. They said, "Keep the family together".

I said, "you've done your time, this is my responsibility."

'Ex-partner's sister took the children and now prevents contact. "She turns them against me. Tells them I'm not their mother. "

Peer support

Peer support, whether this has come about as a result of joining DPN's contact register, by belonging to a local group of disabled parents or through fortuitous contacts, tends to be extremely highly valued by parents (see Table Four, Appendix B). Parents who are part of a mental health project supporting families made the point that speaking to a person at the end of the phone or in a group who has been through something similar to oneself can be really helpful.

Parents who experience depression say that there are times when they would simply not have had the energy or motivation to open up a handbook, however good its contents. They find a locally based, drop in facility particularly useful, although they point out that it is much better if this doesn't involve going too far from home or into unfamiliar territory.

Parents not only value being able to find support, but also being in a position to pass on what they have learned and offer support to others facing similar challenges. At the same time it was pointed out that it is important for peer supporters to be well supported themselves; particularly those who are recovering from mental health problems or who have variable health.

Distance peer support networks such as the one run by Disabled Parents Network are particularly useful to parents who might otherwise not have contact with anyone in a similar situation.

Whilst the parents involved in the consultation are extremely positive about the value of support networks and local groups of disabled parents, it should be kept in mind that this was a very 'active' parent sample, largely recruited through such networks. They also make it very dear at the same time, how important it is to include disabled parents in services, information and support groups aimed at parents in general.

'Networking with other disabled parents is the only reliable and valuable resource.'

'I am very determined and resourceful and see myself as a resource for other parents also schools I like a challenge and there is a solution for most problems. '

'V[ery] difficult to get hold of other adoptive disabled parents. Best info, from disabled peer activists who are also parents. '

'I wish I had known there were other disabled parents.'

'There are other people who have felt as un-normal and useless as myself. I didn't have a clue who or what to ask, I thought it was just one of those things.'

'Challenges differ as children grow. Isolation the worst aspect of disabled parenting -peer support gives enormous confidence.'

'Other parents with children with additional needs. '

'Moral support from others at People First.' 'Local network of parents of disabled children. '

'A couple of friends gave me a little advice. Then it was a case of taking each day as it comes and hoping for the best.'

'When a new problem comes up, find a parent who has been through the process already. Advertise in the local paper if necessary!'

'[Black family project] -super excellent -the only help I can remember.'

DPN & DPPi

With very few exceptions members consistently cited DPN and DPPi as good sources of information and support. This is in some ways not surprising since the questionnaire was initially sent out to members of DPN who might be expected to have positive experience of one or both of these organisations. However the overwhelming ratio of positive to negative mentions (see Table Three, appendix B) and the number of respondents who commented that making contact with DPN or DPPi had been a key factor in getting their support needs met was very striking.

Encouraging as these findings are, they also contain a challenging message for DPN and the National Centre for Disabled Parents. Given that many are having a desperate struggle to get hold of information and support, the evident value to disabled parents of the support offered by DPN and DPPi underlines the need to actively publicise their existence and services systematically and extensively, including "through GP surgeries, family support agencies, social services departments etc, whilst at the same time taking advice on the most effective means of reaching under represented groups.

'Made friends through ParentAbility who reassured me. '

'Sheer luck I came across DPN & other support agencies.'

'Info from PA [ParentAbility]. psychological adaptation to need was with the practical organisations. '

I helped enormously with parenting but my greatest side, and this predated our

'Contact register "gave confidence to go ahead". '

'DPN parents support worker.

'Info on labour & equipment from ParentAbility.'

'I did not realise that there was any support for disabled parents of non-disabled children. '

'Read article about DPN in woman's mag.'

'Info about equipment. 'Advocacy help.'

'Learnt about social services' child minding through a fellow member of DPN.'

'Only real support "wish I'd known earlier I was not alone and DPN existed".'

'DPN & DPPI -advice on bathing, changing, lifting equipment. '

'Enjoy reading about other peoples' experiences [in newsletter]. '

'Other than DPN know of no other useful contact or support groups that were or are particularly useful.'

'Make database and DPN details available to social services departments. '

'Accessible formats only from DPN & DPPI.'

'DPPI Pamphlets and Database [useful].'

There were, however, a few comments for the organisations to take on process and learn from.

'A mother contacted via ParentAbility contact register gave bad advice about ME.'

'Very limited, contacts given impairment based not geographical or situation. '

'Could have helped more with my divorce. '

'Unhelpful; told me that it is illegal to carry a child on lap in electric wheelchairs. '

Children's experiences

In this study of disabled parents experiences, no attempt was made to interview children themselves, but comments made by parents about their children's responses to disability suggest that it would be misleading to think that one could generalise about children's experiences of having a disabled parent, any more than one could generalise about children's relationships with their parents in general.

'Children need to know what disability is about. They need to be on terms with it and they need to know what to do.'

'Children are very adaptable.'

'Children are lovingly adaptable. '

'My child adjusted with ease.'

'I didn't realise that my children would find it so difficult to have a mother who's different. It's to do with status and poverty too. Impact on children's sense of themselves swamps practical issues.'

'Children find it a major adjustment now that I cannot run after them.'

The questionnaire did not ask about disability in relation to the children themselves. There was none the less a surprising amount of information offered about disability in the experience of children, sometimes related to the parent's own condition but also in some cases quite distinct from it.

As mentioned in the section on schools, an unexpected finding is that disabled parents with disabled children may, in some cases, have better access to information and support than disabled parents with non-disabled children. This was illustrated particularly clearly by mothers with visual impairments who said that the services were much better geared up to support children with visually impaired than to assist parents with health visitor visual impairment to look after non-disabled children. Some parents found that their own access to support came about initially through their disabled children's contact with social services. This was also a source of frustration for a parent with visually impaired who did not, as many of her friends did, have a visually impaired child.

'Contact with children's services because of children's visual impairment but they've also been good at meeting my needs as a disabled parent. '

'It's much easier to get information and support in relation to a disabled child. '

'There is no funding for disabled people who have "normal" children. '

'My children have v different disabilities so v hard to collate support. Always up to the disabled person to search out the info. '

'They don't expect parents of disabled children to be disabled themselves.'

Implications and recommendations

Implications of the consultation for the DPN Handbook

Parents who have a strong sense of their rights and entitlements are in a better position to get hold of support. With the publication of the Handbook there is an opportunity for the first time to explain clearly what disabled parents are entitled to and how to get hold of it. The use of plain English, an easy to follow lay-out and suitable visual material will help a wider range of parents to make use of this information.

What the DPN Handbook will cover

The Handbook will make it a priority to explain clearly and simply disabled parents' legal entitlement to information and support. Central to this is Community Care legislation and guidance - legislation upholding human rights and legislation that guards against discrimination on disability or any other grounds. Legislation relating to children's welfare and rights, health services, carers' rights, education and housing are each important too. The following will be covered:

- Legislative and guidance background to disabled parents service entitlements.
- How to make contact with services in the first place, how to get assessments
- How to make sure that all relevant needs are thought through and how to make sure that changes in health or family circumstances are taken into account.
- Making parents aware of their right to see what has been written down about them and to be included in discussions about their children's future.
- How to find personal supporters, advocates and legal help if needed.
- How to make a complaint if parents or their family members are not happy with the service they are given.
- Signposting to sources of support and information.
- Area-based information relating to specific local resources, support organisations and facilities.

Signposting

Whilst some parents will be looking for detailed information about their entitlements under different acts of legislation and government guidance, others will have more individual information needs. Much information of potential interest and value to disabled parents already exists, but it is scattered and hard to get hold of and is often not available in accessible formats. Another task for the handbook will be to signpost parents to useful sources of information and support.

DPPi and the National Centre for Disabled Parents

The consultation has brought together a lot of useful information about local and national support organisations, useful publications, videos, tapes etc. Support organisations, impairment related charities and statutory service providers are invited to add to this list of resources (see contact details at end of report).

Disability, Pregnancy and Parenthood International (DPPi) Information service, based alongside DPN at the National Centre for Disabled Parents, has produced a number of specific information sheets for disabled parents and allied health and social care professionals. It will make sense to integrate the information supplied by parents through the consultation within the database already held at the National Centre for Disabled Parents. Details of what the database covers and how to access it will be included in the Handbook.

Formats

The most popular option was to offer the Handbook in a loose-leaf format. The second most common option ticked was that information should be accessible via the Internet. The significant advantages of this are that it makes information instantly accessible to a wide audience. It has the added advantage that fewer hard copies would have to be produced and stored, whilst special formats such as large print could be sent out on demand.

The need to update information on a regular basis is a potential challenge for DPN as there has to be someone whose job it is to design accessible information and keep it updated, whether for putting onto the Internet or for reproducing and sending out from the National Centre for Disabled Parents.

The fact that most parents ticked a range of options (on average four) when asked in what form information should be made available, underlined a point stressed by a number of parents -i.e. the importance of offering information in a wide range of formats to make it available to as many parents as possible. This should include text supported by drawings and symbols, tape, Braille, versions that could be downloaded from the Internet, video with spoken commentary, audio description,

British Sign Language interpretation and captions, etc (see Table Four, Appendix B).

The announcement, on 18th March 2003, that British Sign Language has been officially recognised as a minority language in the UK underlines the importance of making translation services routinely available at all stages of parenting including maternity services and schooling and ensuring that all information aimed at parents is also available on BSL signed videos.

Whilst it is beyond the scope of DPN working alone, the consultation suggested various exciting possibilities for collaboration between DPN and organisations whose remit includes using specialist expertise to meet the information needs of particular groups such as Deaf people, people with learning difficulties, people with visual impairments etc.

Local information

Several parents made the suggestion that a loose-leaf file could usefully include a local section that would list resources and contacts in a particular area. The preparation of this can best be done by DPN working alongside regional contacts. This idea is being discussed with several local support groups, one of which is currently using regional lottery funding to produce a folder of local information. It is hoped that this group might produce guidelines on the basis of their experience that will help other groups to gather information in their own areas. Although DPN does not currently have the resources to ensure that this happens in every area of the country, in the light of the consultation DPN will now consider both what it can most usefully produce within the limits of the project and also which options might be further explored in collaboration with other organisations.

Recommendations for policy makers and service providers

The consultation findings underline the need for a drive towards making professionals and organisations in the family and parent support sector (whether governmental or non-governmental) more aware of their legal obligation under the Disability Discrimination Act to meet the support and information needs and service entitlements of disabled parents. This is in line with a growing awareness in the voluntary and public sector of the need to be proactive in promoting social inclusion.

The level of support given is currently very dependent on individual relationships between disabled parents and professionals. Certain professional groups appear to be perceived as more supportive than others although there are individual variations within all groups (see Table Two, Appendix B).

Although it was clear from the DPN consultation disabled parents value peer and community support networks extremely highly, it would be a mistake to underestimate the central contribution of statutory services. Rather the question is, how can mainstream health, social, education and family support services establish more effective partnerships that will enable them to work both in a more joined up fashion with each other and at the same time in partnership with voluntary organisations and informal supports?

Some of the negative experiences reported by parents in relation to certain service provider groups raise the question as to how statutory services can develop the characteristics of approachability, flexibility and supportiveness that parents value in much of the help they receive from family, friends, informal community sources and local supports based in the voluntary sector.

Part of Disabled Parents Network's purpose in distributing this report widely to organisations concerned with parent and family support - or with support to disabled adults, some of whom will have parenting responsibilities -is to encourage them to think about making their own activities, services and information more accessible to disabled parents.

Pointers for good practice

- Establish co-ordinated inter-agency procedures for the systematic early identification of disabled parents, with a view to addressing the disabled adults parenting support needs in good time to prevent problems arising and in order to respond promptly and supportively when family needs change.
- Set up links between impairment related organisations, the parent and family support sector, disabled parents organisations and statutory services with the specific aim of identifying and addressing some of the current gaps in information.
- Promote direct payments (including joint-funded packages across health and social services) for disabled adults to purchase assistance with parenting.
- Involve disabled parents in developing co-ordinated training and inter-agency protocols and in monitoring services.
- Prepare accessible service information specifically aimed at parents with chronic illnesses, physical and/or sensory impairments, Deaf parents, disabled parents from black and ethnic minorities those with learning difficulties or with particular mental health needs.
- Printed materials, websites, videos and tapes should genuinely reflect the diversity amongst families in Britain today -including the groups mentioned

above and also reflecting that disabled adults, just as others, may live in step families, mixed race marriages, same sexed marriages, that disabled fathers may be primary carers and so on.

- Explore options for partnership working with disabled parents and their organisations to produce information in suitable formats, locate suitable photographs and drawings etc.
- Take the access requirements of disabled parents into account when designing and fitting buildings, choosing equipment, planning services and training staff.

Recommendations for further research

Much of the research with a bearing on the lives of disabled people and their families has started out from the assumption that disability is a physical, mental, sensory or cognitive characteristic of the individual, that to a greater or lesser extent causes problems for them and for those who live with them. In so far as disabled parents have been the subjects of the research process the focus of this work has been to assess the impact of parental disability upon children or other family members rather than the identification and removal of barriers.

Work that is consistent with the social model of disability defines disability primarily as a social experience, in which factors such as attitudes towards disabled parents and the way in which services are planned and delivered may have just as much, or even more, of an impact on the lives of disabled people and their families as the presence of impairment.

It follows that to carry out this process effectively will require two things of the research process. Firstly the intention of the research should be the identification and dismantling of barriers to parenting, and the promotion of effective support.

Secondly, involving a relevant range of disabled parents in identifying research aims, deciding on the methods to be used, evaluating and disseminating the findings of the research is of key importance (Olsen and Wates 2003).

In any given subject a range of work might be undertaken from small scale action research around an aspect of effective inter-agency co-operation such as joint training or information sharing, through general surveys of professional practice in relation to a particular area such as housing, to large scale statistical studies to establish a more informed base for the development of services.

A relatively straightforward way to access this information would be by including questions in the next national census to determine the number of parents of

dependent children, defining themselves as having a long term illness, impairment, mental health problem, learning difficulty or being Deaf.

There is at this point an almost complete lack of statistically based information relating to the numbers or situation of disabled parents, including those with physical and sensory impairments, illnesses, learning difficulties and mental health difficulties. Disabled Parents Network would like to see the development of quantitative research, which can be used alongside qualitative studies to provide specific information on the following:

- The numbers of disabled parents (including foster and adoptive parents) with dependent children who have a long term illness or impairment, mental health problem or learning difficulty.
- Numbers of disabled grandparents.
- Geographical distribution, including rural/urban location.
- Household type, marital status, gender and age.
- Occupational status.
- Housing tenure.
- Car driving and/or other transport options.
- Income levels, including benefits received/applied for.
- Nature of impairment. At what stage onset occurred in relation to parenting.
- Whether children are also disabled.
- Whether disabled parents are living with their children full-time, part-time, having occasional access or no access to their children and for what reasons.
- Proportion of children in long-term care, fostering or in line for adoption whose parents are disabled.
- Accessibility of parent education, maternity services, primary health care, and family facilities, including shops, sports, leisure, playgrounds, playgroups, schools etc.

Given the increasing recognition of the link between poverty and households that contain disabled members and more particularly disabled adults, the economic

situation of families must be recognised as a key factor in an analysis of the situation of disabled parents.

The consultation highlighted a number of areas where further investigation is needed. These include how to develop disabled parents' access to mainstream maternity and parenting services, access to specialised resources and housing, the use of direct payments to support parenting, outcomes for parents who make complaints, access to hospital, advocacy and legal services and the application of the Disability Discrimination Act to schools' communications with disabled parents.

Conclusion

‘It shouldn’t be down to luck ... ‘

The quote chosen as the title for this report is part of a longer quote made by a visually impaired mother:

‘It shouldn't be down to informal conversations with other parents and the luck of the draw with professionals as to whether you get information or not. Information about visual impairments should be systematically included in the manuals, in the policies, in the handbooks.’

Parents expressed the view that it should not be down to luck or determined detective work by a few individuals who manage to track down information and show that they have a right to receive a service or accommodation to their needs in respect of meeting their parenting responsibilities and/or are lucky enough to find a professional who provides them with good support. The newly issued Fair Access to Services Guidance confirms that disabled adults' right to support with social tasks and responsibilities, including parenting, is upheld by Community Care legislation (DH 2002a and b) and by the Children Act 1989.

'Social inclusion' remains a fine-sounding but meaningless term unless it is translated into specific initiatives and practical commitments. Parents stressed throughout the consultation that their needs as parents with chronic illnesses, physical and/or sensory impairments, Deaf parents, those with learning difficulties or dealing with mental health issues should be routinely and systematically addressed as part of mainstream provision to parents and families. By the same token services to and information aimed at disabled people should systematically and routinely address parenting needs.

It is for this reason that the DPN management committee has decided to distribute this report on the consultation as widely as possible amongst service providers in both the voluntary and statutory sectors as well as sending it out to DPN members and other respondents.

We are sending the findings to all of the organisations mentioned by parents in the questionnaires and others who have expressed an interest. This is in line with the need outlined above to bring the information and support needs of disabled parents to the attention of professionals, reminding them that they have a responsibility to act on these. It will also highlight to those groups that the Disabled Parents Network Handbook is in the offing and invite them to notify us of information that they think relevant to include.

If you are aware of organisations, groups or service providers in either the statutory or voluntary sectors that would be interested to receive a copy of this report, or if you have information that you think should be included in the Handbook or the National Centre for Disabled Parents' database, please contact DPN (see Appendix C for contact details).

Appendices

Appendix A: The Questionnaire

Disabled Parents Network: Handbook Questionnaire

- 1 How easy or difficult was it to get hold of the information you needed about parenting / where to find support with parenting?

Please fill in by putting 1,2,3,4, or 5 in each box as appropriate (see below):

- When you were a teenager at school
- When you were thinking about becoming pregnant
- When you were expecting your first baby
- At the time of the baby's birth
- In the first weeks and months after the baby was born
- When your child/ren were pre-school age
- When you were looking for a school for your child/ren
- Once your child/ren were at school
- When you or your child/ren's needs changed unexpectedly
- When your child/ren were teenagers
- Other, please state:

1 = I had no information at all at this stage

2 = I did not have enough information at this stage

3 = I'm not sure whether I had enough information at this stage or not

4 = I got some useful information at this stage

5 = I had all the information I needed at this stage

What is the best information/advice you found as a parent?

Where did this come from?

.....

Please complete the sentence "I wish I had known earlier that ..."

.....

2. What information should be in the Disabled Parents Information and Rights Handbook?

Please tick if:

It was difficult to find information about:	There are good sources of information	
		How pregnancy, childbirth or parenting might change, or be changed by, your particular illness or condition?
		Help from health and social services to assist with parenting.
		How to get hold of equipment to help you meet your children's care needs?
		How to get changes made to your home to help your parenting needs e.g. lifts, rails, ramps, flashing light alarms, etc.?
		Access to schools, communication with teachers etc.
		How to get hold of financial support or welfare benefits to help with parenting?

Please write down any useful information you have found on any of the above, that you think should be included in the Handbook.

.....

Please give details of groups, services or organisations that other disabled parents might find useful (this could include local groups)

.....

(Please write on a separate sheet if you have more to say.)

3. Which professionals and organizations have you found helpful as a parent?

Please tick if:

	You have had contact	This was a useful source of information	They put you in touch with other organizations or agencies	Not happy with support given
Ante-natal teacher				
Midwife				
Health visitor				
Family doctor (GP)				
Consultant				
Community nurse				
Pre-school group				
Day Nursery				
Child's teacher(s)				
Education Welfare Officer				
Educational Psychologist				
Social Worker: Adult Division				
Social Worker: Children's division				
Occupational Therapist				
Physiotherapist				
Mental health support/counseling service				
Housing Officer				
Respite care				
Family Support Centre				
Family Assessment Centre				
Local association of/for disabled people				
Local group of/for disabled parents				
Disabled Parents Network				
DPPi Information				
Voluntary organization:				

Please say which:				
Other, please say what:				

Please comment on the following if you would like to:

(Write on a separate sheet if you have more to say.)

- A Which professionals have been most helpful to you as a parent?
- B How easy or difficult has it been to get hold of information about how to get support when your needs or your children's needs change suddenly?
- C Have you used advocates, personal supporters or taken legal advice? How did you get hold of them?
- D Have you ever made a complaint because you were not happy with the support and help you were given? How did you go about it? Did things get better after that?

4. Making the Handbook more accessible to all disabled parents.
Which format should the Handbook be in? (Tick as many options as you like.)

- In book form – large
- In book form – pocket sized
- In a ring binder so that updated pages can be added
- Information held on a computer and sent out on request
- Information can be downloaded from the Internet
- Interactive CD-Rom
- Video with sign language interpretation
- On tape
- On Braille
- Other format, please describe:

Please comment on whether you were able to find information in plain English and in the form you needed – e.g. in large print, on tape, with sign language interpretation or in different languages?

5. About You

Are you Female Male

What age group are you in? 16-18
 19-29
 30-39
 40-49
 50+

Please would you describe your ethnic origin. Tick one box only.

White

- British
- Other White background, please state:

Asian or Asian Britain

- Indian
- Bangladeshi
- Pakistani
- Chinese
- Other Asian background, please state:

Black or Black British

- Caribbean
- African
- Other Black background, please state:

Mixed

Any mixed background, please state:

Other

Any other ethnic background, please state:

In your own words, how would you describe your condition/impairment/illness/disability?

.....
.....

How long has this condition/impairment/illness/disability been part of your life?

.....
.....

How many children do you have?

How old are your children?

Are you a grandparent? Yes
 No

Are you a lone parent or do you have a partner?

I am a lone parent

I have a partner

Do you live in:

- England
- N Ireland
- Scotland
- Wales
- Eire

Thank you for your help.

Appendix B: Tables

Table One Disabled parents' access to information at different stages of parenting

Stages	1	2	3	4	5	Poor Info (1+2)	Good Info (4+5)	Ratio of Good to Poor Information
Teenager	61	7	7	5	3	68	8	0.12
Pre-conception	30	31	14	10	5	61	15	0.25
Expecting	15	34	9	27	13	49	40	0.82
Birth	13	33	11	11	11	46	22	0.48
Post natal	11	35	16	29	8	46	37	0.80
Pre-school	12	18	15	35	9	30	44	1.47
Seeking schl	16	15	11	22	11	31	33	1.06
Ch at school	13	15	7	12	12	28	24	0.86
Ch in teens	10	4	6	8	2	14	10	0.16
Needs change	23	20	10	6	1	43	7	0.16
Other	1	6	1	4	1	7	5	0.71

Key

- 1= No information
- 2= Not enough information
- 3= Not sure
- 4= Some information
- 5= Good information

Table Two Professional groupings: amount of contact and supportiveness

	c	i	r	s	total irs	sir	is	rs	ir	x
Professionals										
GP	103	18	13	57	88	6	4	2	1	18
Health Visitor	102	31	26	54	111	13	5	5	2	19
Midwife	95	24	5	46	75	3	7			15
Consultant	85	16	3	32	51	1	8			10
Child teacher	75	10	4	46	60	2	5			17
OT	71	22	10	36	68	9	7		1	18
SW Adults	66	17	17	23	57	9	3	3		33
Antenatal tchr	65	22	4	19	45	2	5			18
Pre-sch tchr	64	11	0	25	36		5			8
Day nursery	61	8	2	27	37	1	2			6
SW children	58	8	6	17	31			2	1	30
Physio	55	10	4	26	40	3	4			12
Comm Nurse	36	10	4	12	26	3	2			6
M H Counsellor	32	10	7	19	36	5	3	1		7
Housing Officer	29	2	2	4	8	1				20
Educ Psychol	21	2	1	4	7		1			8
Educ Welfare	17	4	2	5	11	1	1		1	8
Family centre	13	2	2	5	9		1			4
Respite care	7			1	1					3
Fam Asst Centre	5	1	1	2	4	1				2

KEY

c= contact

i = information

r= useful referral

s= good support

Total irs = total of positive mentions: (i+ r + s)

sir = support, information and referral from same source

i = information and support from the same source

rs = referral and support from the same source

ir = information and referral from same source

x = not happy with support given

Table Three Peer support sources ranked by amount of contact

	c	i	r	s	total irs	sir	is	rs	ir	x
Peer support										
DPN	83	46	18	42	106	16	10	1	1	3
DPPi	52	29	10	21	60	8	4	4	1	2
Loc Disby Soc	38	13	6	16	35	3	4	1		2
Loc DP group	27	10	10	20	40	8	1	2		

KEY

c= contact

i = information

r= useful referral

s= good support

Total irs = total of positive mentions: (i+ r + s)

sir = support, information and referral from same source

i = information and support from the same source

rs = referral and support from the same source

ir = information and referral from same source

x = not happy with support given

Table Four Format options ticked by parents

Format	Number of respondents that ticked option	Percentage of respondents that ticked option
Ringbinder	76	63.3
WWW	70	58.3
Tape	54	45.0
BSL Video	52	43.3
Large book	51	42.5
Small book	51	42.5
Braille	50	41.7
By request	45	37.5
CD-Rom	44	36.7
Other		
Large print	8	
Symbols	3	
Telephone info line	2	
Drawings	2	
Yellow paper	1	
Audio described video	1	

Appendix C: Contact addresses and information

DPN and DPPi at the National Centre for Disabled parents

The National Centre for Disabled Parents
Unit F9
89-93 Font Hill Road
London
N4 3JH

Disabled Parents Network runs a peer support contact register that is open to all disabled parents, sends out a quarterly newsletter to its members, runs a parent-to-parent helpline and campaigns actively for improvements in services to disabled parents.

Telephone: 0870 241 0450
Email: information@DisabledParentsNetwork.org.uk
www.DisabledParentsNetwork.org.uk

Disability, Pregnancy and Parenthood international (DPPi)
Publishes a quarterly international journal and runs a UK based information service for disabled parents and those who work with them.

Freephone: 0800 018 4730 (Information service Mon-Fri 9.30-5pm)
Textphone: 0800 018 994920
Admin: 020 7263 3088
Fax: 020 7263 6399
Email: info@dppi.org.uk
Website: www.dppi.org.uk

References

- Chowdry, S.** (2002) *Deaf Parents: Gaps in Services*. A maternity services discussion video with English subtitles. Deaf Parenting Project, London. Disability, Pregnancy and Parenthood International
- Clarke, K., Sarre, S., Glendinning, C. and Datta, J.** (2001) *Providing family support in primary care: evaluation of the WellFamily Service*, Univ of Manchester NPCRDC and Family Welfare Association.
- DH** (2002a) *Fair Access to Care Services. Practice Guidance*. London: Department of Health
- DH** (2002b) *Fair Access to Care Services. Guidance on Eligibility Criteria for Adult Social Care*. LAC(2002)13. London: Department of Health
- Goodinge, S.** (March 2000) *A Jigsaw of services: SSI inspection of services to support disabled adults in their parenting role*. London: Department of Health.
- McConnell, D. and Llwellyn, G.** (2000) Disability and discrimination in statutory child protection proceedings *Disability and Society* Vol 15 No 6
- Olsen, R. and Clarke, H.** (2003) *Parenting and Disability: Disabled Parents' Experiences of Raising Children*. Bristol: The Policy Press.
- Olsen, R. and Wates, M.** (2003, forthcoming) *Disabled Parents: Examining Research Assumptions*. Review of research and policy development in relation to disabled parents for Research in Practice series of research interviews. Dartington
- Tracey, B.L.** (2002) *Silent Partners? The problems for Deaf parents in accessing appropriate information and support from Health, Education and Social Services for themselves and their (predominantly) hearing children*. Submitted as BSc Third Year dissertation, University of Bristol School for Policy Studies. Queries to: bltracey@blueyonder.co.uk
- Wates, M.** (1997) *Disabled Parents: Dispelling the Myths*. Cambridge: National Childbirth Trust/Radcliffe Medical Press
- Wates, M.** (2002) *Supporting Disabled Adults in their Parenting Role*. York: Joseph Rowntree Foundation