

It shouldn't be down to luck..

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

by Michele Wates



Disabled Parents Network Handbook Project

May 2003

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.

For further information, to request copies of this summary in print or on tape or to provide information for the handbook please contact:

Michele Wates, DPN Handbook Project
C/o The National Centre for Disabled Parents
Unit F9
89-93 Fonthill Rd
London
N4 3JH

Telephone:
0870 241 0450

Fax:
020 7263 6399

An extended report on DPN's consultation with disabled parents *It shouldn't be down to luck* can be read or down-loaded from DPN's website:

www.DisabledParentsNetwork.org.uk

E-mail: info@DisabledParentsNetwork.org.uk

Design by Oxford Designers & Illustrators
Printed by Oxfam Print Room
May 2003

Contents

| | |
|---|-----------|
| Introduction | 2 |
| Support to parents is crucial to children's welfare | 2 |
| The need for a disabled parents' handbook | 2 |
| Why consult with disabled parents? | 2 |
| How the consultation was carried out | 3 |
| An 'active' sample | 3 |
| | |
| Summary of findings | 4 |
| Providing mainstreamed, planned support to disabled parents | 4 |
| Prioritising practical supports | 4 |
| Direct Payments | 4 |
| Community supports | 5 |
| Social inclusion only possible when practical steps are taken | 5 |
| 'It shouldn't be down to luck...' | 5 |
| Recommendations for further research | 5 |
| | |
| Implications and recommendations | 7 |
| What the DPN Handbook will cover | 7 |
| Signposting | 8 |
| DPPi and the National Centre for Disabled Parents | 8 |
| Formats | 8 |
| Local information | 9 |
| Recommendations for policy makers and service providers | 9 |
| Pointers for good practice | 10 |
| | |
| Table | 11 |
| Professional groupings and peer support: amount of contact and supportiveness | 11 |
| | |
| Contact details | 12 |

Introduction

'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 should be systematically included in the manuals, in the policies, in the handbooks.'

(A disabled parent)

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 and those with particular mental health needs to access information, resources and support to help them fulfil their parenting responsibilities.

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.

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 SSI 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.

Further questionnaires were therefore targeted at parents under-represented in the DPN responses; this included disabled parents from black and ethnic minorities, Deaf parents, single fathers, parents with learning difficulties and those dealing with mental health issues.

Though not all of the parents consulted would describe themselves as disabled, the term 'disabled parent' is being used inclusively throughout this report to identify systematic disadvantage rather than to describe individual or group characteristics.

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.

Summary of findings

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*, whilst information aimed at disabled people should cover *parenting* issues. Information needs to be provided in a wide range of accessible formats.

'It shouldn't be down to luck...'

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 and/or are lucky enough to find a professional who provides them with good support.

'Social inclusion' remains a fine-sounding but meaningless term unless it is translated into specific initiatives and practical commitments. The requirements of disabled parents 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 make a point of including parenting needs.

Recommendations for further research

DPN's consultation with disabled parents highlights a number of areas in which further research is needed. Some of this work might be initiated at national level by the relevant professional bodies looking at issues such as disabled parents' access to ante-natal education and parenting support, maternity services, primary health care, equipment and practical supports, hospital, advocacy and legal services. There is also a need for work at neighbourhood level to check out disabled parents' access to local facilities used by parents and families including parent classes, maternity units, doctors' surgeries, shops, sports and leisure complexes, playgrounds, playgroups and schools.

There is a need to develop inter-agency approaches to supporting disabled parents across health, social services, education and the voluntary sector. How can Deaf parents, parents with physical and/or sensory impairments, chronic illnesses, with learning difficulties or

with particular mental health needs be effectively keyed in to services and support at routine and crisis access points, in ways that reinforce rather than undermine their parenting role?

Areas of particular concern highlighted by disabled parents' responses are: how to facilitate access to and support with direct payments; processes and outcomes for parents who make complaints; and exploring difficulties with accessing housing services. It is timely to look at the application of the Disability Discrimination Act 1995, further sections of which are due for implementation by 2004, to the provision of services, goods and information, including schools' communications with disabled parents.

There is at this point an almost complete lack of statistically based information into the numbers or situation of disabled parents. This makes it difficult to make appropriate provision within statutory services, the voluntary and commercial sectors. A relatively straightforward way of accessing a great deal of useful information would be to include questions in the next national census that would make it possible to determine the numbers of parents of dependent children who describe themselves as having a long term illness or impairment, mental health problem, learning difficulty or who are Deaf.

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 should be recognised as a key factor in any analysis of the situation of disabled parents.

Implications and recommendations

What the DPN Handbook will cover

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.

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.

- 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.

It would be easier to keep information about e.g., changes in legislation and service provision updated. The need to update information on a regular basis is also 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 wide a range of 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).

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).

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 (see Table) 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 service 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-sex 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.

Table

Table Professional groupings and peer support: 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 group | 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 |
| 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
is = information and support from same source
rs = referral and support from same source
ir = information and referral from same source
x = not happy with support given

Contact details

DPN and DPPi at the National Centre for Disabled parents

The National Centre for Disabled Parents
Unit F9
89-93 Font Hill Rd
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

E-mail: 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