







## Supporting disabled adults as parents

The National Family and Parenting Institute undertook research into improving supportive practice for disabled parents. The study drew on discussions with parents and visits to four local authorities which have already begun to develop work in this area. Richard Olsen (Leicester University) and Helen Tyers (independent social worker and a disabled parent) found that:

-  Effective support for disabled parents is still thin on the ground, though many local authorities are beginning to recognise the importance of this group of parents.
-  Valued support can involve substantial packages of assistance; but it can also involve low-cost imaginative solutions devised with parents.
-  Direct payments (cash in lieu of direct services) may be particularly appropriate in enabling many disabled adults to fulfil essential parenting roles.
-  Legislation in this field can cause confusion, but the researchers found some practitioners drawing on both adults' and children's legislation flexibly and creatively to support disabled parents in the best interests of the whole family.
-  Good joint working between social services and key agencies (health, housing, education, leisure) and between different social services teams is much needed but insufficiently developed for disabled parents.
-  The researchers recommend that professionals should 'think parent' and view disabled parents in the same way as non-disabled parents: the vast majority want to parent their children well. They may require additional support to do this, including where mainstream sources of parenting and family support for non-disabled parents are inaccessible to disabled people.

## Background

Previous research had shown that local authorities have begun to take seriously the parental responsibilities of disabled adults through the development of policies and protocols. However, practitioners often report a lack of confidence in supporting disabled parents, partly because there can be confusion about whether such support comes under an adult or child social work remit. This is reinforced by the perceived split between those working to children's and adult legislation. This project aimed to provide practitioners with ideas and examples of creative ways of meeting disabled parents' needs.

## What support do parents value?

Part of the project involved hearing from disabled parents about the kind of support they found helpful and *would* find helpful. These factors are summarised below.

### *Access to information*

Timely, accurate and accessible information: in a range of formats (e.g. school reports in Braille, on tape or in large print) and available on an *equal* basis to that received by non-disabled parents.

### *One size does not fit all*

Professionals seeing parents as individuals. There were many different ways in which parents wanted services to respond to them and their families. Some valued having a personal assistant, who would enable them to take their children swimming and to transfer them between the poolside and the pool safely, for example. However, one parent had reservations.

**"I prefer being in a setting where I am still doing the parenting... I don't want to be tagged on to the end of someone who can see, because it gives people the excuse they need to talk to them and not to me."**  
(Pauline)

### *Support which fits in with family life*

Parents wanted support which fitted in with, rather than took over, family life. Positive examples included:

- support from a GP and health visitor in getting one father's child a place at nursery from the age of two and a half;
- the provision of vouchers from the local authority which could be used to subsidise the cost of public transport when going out as a family; and
- attending a group for parents with learning difficulties, which helped boost one mother's confidence in her abilities as a parent.

Parents valued support being offered in ways which helped them retain parental control and choice. Direct

payments and purchase of personal assistance provided some with a means to do this.

### *The personal qualities of key professionals*

Views about support were consistently tied to the personal qualities of the professionals who dealt with them. This emphasises the importance of training key frontline staff in disability issues, as well as in the skills necessary to communicate effectively with parents (putting parents at their ease; allaying fears of asking for support). These personal qualities could overcome a lack of specialist training.

**"My social worker isn't trained in visual impairment, but she is really approachable and I have been able to develop a really good, supportive relationship with her."** (Diane)

### *Someone fighting your corner*

Support from advocates or other professionals who parents would feel were 'fighting their corner' was considered to be an important way to reduce barriers to fair treatment. This also helped in supporting parents to access services and other entitlements, such as benefits, a fair hearing in court, and information about assessments.

### *Flexible support*

Many parents pointed to inflexible ways in which some support is currently offered. Many wanted support which could be used at shorter notice and more flexibly as their needs and their children's needs changed.

### *Culturally appropriate support*

Support for disabled parents should be offered in culturally appropriate ways. One mother, with two small children at home, was concerned that they were growing up with "onion rings and chips" as their favourite food, given her difficulties in preparing traditional Asian food. She was then provided with an Asian home care worker of a different faith who did not know how to cook the appropriate meals.

### *Timely and responsive support*

Parents who received prompt support were quick to highlight the benefits to them and their families.

**"I was amazed that Bromley swung into action so quickly, sending round an occupational therapist to assess my physical needs, and then guys to do the work involved."** (Bob)

Other parents reported significant delays in obtaining support such as home adaptations. Often, by the time adaptations had been made, the original need had been replaced by other needs (for example, a baby had grown into a toddler).

### ***Imaginative support***

Imaginative support often did not involve care packages or direct payments. Rather, it was about a wider perspective of parenting support needs and an imaginative response worked out with parents. Examples included:

- assistance to set up and sustain a peer support group; and
- a school developing a 'walking bus' (a safe, organised walk to school by primary school children supervised by parents), which overcame one father's difficulties in accompanying his child to school and his safety concerns about letting his child walk alone. (The 'walking bus' was also beneficial for other children and parents.)

### **Many different roads to providing support**

The second stage of the project involved visits and interviews in four authorities known for developing their practice with disabled parents. The four authorities have taken three different strategic approaches to supporting disabled parents:

- the development of innovative practice from the bottom up, with policies and protocols written subsequently to reflect changing practice;
- the development of policies and protocols, with significant input from disabled parents themselves, aimed at improving practice led by the top; and
- placing support for disabled parents within a broader strategic commitment to the principles of independent living across social care, housing, health and employment.

### **Messages for senior managers and policy makers**

While no single authority would claim to have 'got it right' entirely, these different approaches indicate that local authorities can take different strategic paths in their work with disabled parents.

Their experience suggests the following messages and suggestions for senior managers and policymakers committed to improving practice in this area (the full report details the different and specific ways in which these authorities have developed practice for this group of parents).

- Think disabled parents, and formulate a clear policy that stipulates that 'disabled parent' does not automatically translate to 'child in need'.
- Make decisions about where funding will come from, ensuring that funding can be used flexibly to meet different needs in different ways (there should be a way of resolving budgetary issues within and between agencies that does not compromise the support offered).

- Improve communication and working across adults' and children's social services teams and with other key agencies, such as health, housing, education and leisure.
- Access and support should be based on clear access arrangements, coherent assessment approaches and imaginative support.
- Assessment processes should prevent parents being passed from team to team; ensure that assessments (adults' or children's or both) fully include parenting support needs; and allow for quick and timely assessments of often essential and immediate support needs.
- Provide accessible, clear and non-stigmatising information and signposting to services for disabled parents.
- Unlock the potential of direct payments to provide flexible support to disabled adults with parenting support needs.
- Support frontline workers and middle managers to use children's and adults' legislation and guidance in working creatively, collaboratively and supportively with disabled parents and their children.
- Authorities need to be clear about the balance and relationship between services designed for 'young carers' and services designed to support disabled adults in their parenting role.
- Equipment and adaptations can make all the difference to some parents in enabling them to parent their children fully and confidently.

### **Common characteristics**

Within the very different approaches, the researchers identified three common characteristics across all four authorities.

#### ***People approaching the service who are passed between different teams***

These were often people who were considered to have fallen between services or not to have met eligibility criteria for accessing services. This was found to be particularly true for parents whose impairments were not severe in relation to meeting their needs as an individual but whose support needs had changed on becoming parents. These cases, where the parent is perceived to be unable to meet their child's needs, are most likely to be referred to child care teams where, in turn, parental disability may go unrecognised and the parent go unsupported.

#### ***People with a good knowledge of, and/or previous work experience in, a childcare setting***

Many people directly involved in developing supportive practice with and for disabled parents possessed these qualities and therefore did not have a fear of the childcare process and legislation. They were often confident in their personal knowledge and skills

at identifying, and meeting, underlying need. They were also confident of when there was a need to approach children's services for advice or referral. The researchers found that professionals providing effective support were comfortable recognising where they lacked knowledge and approaching others for advice.

### *A performance indicator relating to the support of disabled parents*

Several managers responsible for strategic decision-making in relation to disabled parents considered that the introduction of such an indicator would help galvanise activity at local levels.

**"In a performance culture, if it doesn't get measured, it doesn't get done."** (A manager)

### Principles of good practice with disabled parents

The following principles have been informed by discussions with disabled parents and professionals, and by what research from a 'social model' of disability perspective has suggested about disabled parents and the provision of assistance to them.

- Focus on rights and entitlements.
- Focus on how barriers to fulfilment of the parenting role can be tackled (inappropriate services can be compound barriers).
- Be needs-led.
- Promote parental choice and control.
- Involve working in partnership across teams and agencies, and with parents themselves.
- Work from a sound knowledge base of practice, policy, legislation and research.
- Involve management commitment and strategic direction.
- Underpin rather than undermine parents in fulfilling their parenting role.
- Be non-discriminatory to disabled people as parents.

### Conclusion: 'Think parent'

All parents need assistance with parenting. For many disabled parents, standard sources of support are inaccessible or not adapted. Good practice will involve challenging assumptions that a disabled parent automatically equates to a child in need. Suitable, timely, imaginative and flexible support with parenting will generally be the best way to ensure that their children's needs and best interests are met. This requires professionals to have a primary focus on the barriers and solutions identified by parents themselves, and to guard against sidestepping parental support issues in favour of invoking children-in-need

procedures unnecessarily. Where children-in-need assessments are carried out, as will be appropriate in some cases, the researchers recommend that full attention should also be given to identifying and meeting parental support needs.

### About the project

The research had two stages. The first asked parents about any support that they had found particularly useful. The project was publicised widely among national voluntary sector organisations in contact with parents and/or disabled people, and provided website, email, freephone and freepost ways of reaching the researchers. Fifty-two parents responded. The second stage involved more detailed work in four local authorities - Camden, Doncaster, Kingston-upon-Thames and Nottinghamshire - chosen because they had already begun to develop work in this area. Visits to these authorities lasted between two and three days; they included interviews with a range of policymakers and practitioners, mainly in social services departments (adults' and children's teams), with disabled parents (in groups and individually), and with other key local professionals such as direct payments support workers.

### How to get further information

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