

November 2002

## **Together from the Start: Practical guidance for professionals working with disabled children (birth to 2) and their families.**

Consultation response from the Joseph Rowntree Foundation

### **General comments**

#### Accessible formats

The Guidance should use a larger font: although it uses a sans serif typeface and the spacing between lines is good, the font size is too small.

There is no indication anywhere in the Guidance that it is available in other formats: on tape, in large print, braille.

#### Social model of disability

Although there seems to be an implicit assumption that the Guidance is based on a social model of disability, the full implications of this are not always brought out. A particular opportunity is missed in paragraph 1.4 and we make suggestions below for how to remedy this.

The Guidance uses both 'medical model' and social model language and this can be confusing: It would be more helpful if the Guidance used the following language:

Impairment – to refer to functional limitations

Disabled children – to reflect an approach which recognises that children with physical, sensory and/or cognitive impairments are disabled by social, environmental, economic and attitudinal barriers.

The advantage of using clear, social model language is that it enables the separating out of impairment and disabling barriers, and thereby, makes it more likely that services will tackle needs arising from both. Conflating 'disability' (i.e. disabling barriers) and impairment makes it difficult to adequately address either sets of needs.

#### Disabled parents

There is little recognition in the Guidance that some parents of disabled children are disabled themselves (except for a passing reference to this possibility on page 22). Childhood impairment is associated with disadvantage and poverty, and so too are parental ill-health and impairment. Some conditions are hereditary. It is particularly important to recognise the

support needs of parents with learning difficulties – and perhaps especially those with mild to moderate learning difficulties who may not already be in contact with adult services.

Over the last two years, the Joseph Rowntree Foundation has supported a Task Force on Disabled Parents. Representatives from the statutory and voluntary sector, and disabled parents themselves have identified a number of important issues which have informed our response to this Guidance.

Two particular issues are:

1. The importance of recognising disabled parents' entitlements, under community care legislation, to assistance with parenting tasks. Local authorities' obligations in this respect have been highlighted in the recent Policy Guidance on Fair Access to Care Services. If children's social services and other statutory agencies wish to work together to effectively meet the needs of disabled children they will need to recognise that some parents will be disabled themselves. It will therefore be important to encourage joint working with adult social services.
2. There is some evidence that parents with learning difficulties make up about a third of parents whose children are taken into care. A number of these children have physical, sensory and/or cognitive impairments. It is clear that effective early support is particularly important for these parents and their children if they are to be given any chance of family life.

It is very important, therefore, that the Guidance encourages professionals to:

- recognise that parents of disabled children may have their own support needs and be entitled to assessment and support under community care legislation
- recognise that support to families of disabled children needs to take into account parents' own access needs.

Our specific comments below include some suggestions as to how the Guidance could encourage this.

Fair Access to Care Services Policy Guidance recognises that assistance with parenting tasks should be covered in adult community care assessments and service provision. It would therefore be useful to refer to FACS as a relevant part of the statutory framework in which professionals are working.

### Child protection

This guidance is generally unclear about its role in the context of child protection. The

Guidance could have an important role to play in encouraging the kind of support which may prevent disabled babies and young children being at risk of abuse or neglect. Anecdotal evidence from parents with learning difficulties in particular indicates that – once child protection procedures are instigated – they find it even more difficult to access the support they need in order to parent effectively and are therefore likely to lose their child into the care system. It would therefore be useful if the Guidance stated explicitly that agencies should ensure that its approach is followed even when there are child protection concerns. We make a specific comment below about the possible role of the proposed Family Support Plans.

### Foster carers

The language used throughout tends to assume that the carers of a disabled child are their biological parents. This will not always be the case, even for very young children. Where a child is placed with foster carers, services will need to work in partnership with the foster carers and fully acknowledge their role. It would be useful if the Guidance stated this somewhere.

### Framework for Assessment – chapter on disabled children

As the Practice Guidance (which contains a chapter on disabled children) was not issued at the same time as the *Framework for Assessment*, it is particularly important to provide clear signposting about the Practice Guidance and how to get hold of it. We suggest that the full title of the Practice Guidance – *Assessing Children in Need and their families: Practice Guidance* - is provided, together with the website address from which it can be downloaded: <http://www.doh.gov.uk/scg/qptch.htm>

## **Specific comments**

### Page 5 top of page.

Research indicates that parents and carers often lack information about what they are entitled to under both existing legislation and guidance and local policies and procedures (Beresford, 1995) . They would welcome clear information about how long they can expect to wait for assessments and services, who is eligible and what to do if they want to complain. Professionals also sometimes lack this information about other agencies.

We therefore suggest adding the following:

‘Views from parents and professionals alike cite the following factors as having positive impacts on service development and provision:

- *clear information about entitlements, waiting times and eligibility criteria, and how to complain.*

There is also evidence that service development and provision benefits from clear procedures and processes for recording, collating and analysing unmet need. We therefore suggest adding the following bullet point:

- *recording, collating and analysing unmet need and using this to inform service development and commissioning.*

## Page 5

### 1.4 Which children are we talking about?

This section does not recognise that the extent and nature of a child's need may not always be determined by the extent, or nature, of their impairment. There seems to be an assumption that the more significant the level of impairment the greater the need. There is therefore little room for recognising the effect of disabling barriers on the level and nature of need.

Section 1.4 starts off with saying 'The needs of children and families will vary along many dimensions' but does not acknowledge the importance of disabling barriers as a dimension. We suggest, therefore, adding another bullet point to this section:

- *the circumstances in which children experience their impairment will have implications for the nature and extent of their needs. Environmental, economic, social and attitudinal factors may either increase or decrease the effect of impairment.*

This recognition is also in line with the approach recommended by the Framework for Assessment of children in need.

## Page 7

### 1.7 Aims for service provision

Some children and their families will be living in housing which is unsuitable for a child with significant health care needs (Oldman and Beresford, 1998) ; some may be living in rural areas with no access to public transport; some may have no extended family living nearby to assist; some may have extended family but they may hold negative attitudes about impairment and be unwilling to help. It is very important that the aims for service provision recognise the needs which will arise not so much from impairment per se but from the context in which it is experienced.

We therefore suggest the following addition:

‘To support the child in all aspects of their development, including:

- *providing support to the child and family to address difficulties arising from the context in which the child and family experience impairment.*

Again, it is important that services aim to meet the needs of disabled parents. We therefore suggest the following additional point:

‘To provide families with the support they need in bringing up their children, including:

- *support which parents/carers may require because of their own needs for assistance, for example help with parenting skills for a parent with learning difficulties; practical help for a parent with physical impairment.*

Page 10

### [2.3 Communicating the news]

.....third para. Beginning ‘Parents will react differently.....’ Add:

*Some parents and carers will particularly appreciate being put in touch with other parents/carers whose child has the same condition/impairment.*

There is recognition of this elsewhere in the Guidance but it is important to add in here a paragraph which suggests what forms of immediate support should be offered.

Page 13

### 2.6 Ongoing assessment

There should be a reference somewhere to the importance of recording unmet need and feeding this information into the development and commissioning of services. For example, the following sentence could be added to the first paragraph in this section:

*Need which is expressed by parents/carers but which cannot currently be met should be recorded, aggregated and used to inform the future allocation of resources and the development and commissioning of services.*

One example of how important this is comes from various pieces of research which indicate the importance of helping parents/carers of disabled children to deal with sleeping problems. Existing services tend not to accept referrals until children have reached a certain age, usually 5. Yet the sleep problems of very young disabled children can have a very significant effect on families, and are a very common reason for parents requesting respite care outside the home for very young children (Morris, 1998). If support with tackling sleep problems was available from a very early age, many of these difficulties would be avoided.

Page 13

## 2.6 Ongoing assessment

Again, it is important that services recognise that parents/carers may have their own support needs.

Add another bullet point:

- *develop understanding of the range of support needs associated with particular circumstances, for example where parents/carers have learning difficulties; personal care and/or mobility needs; health care needs arising from, for example, HIV/AIDS, sickle cell anaemia.*

Page 13

## 2.7 Assessment outputs – the Family Service Plan

Although one of the bullet points refers to reviewing a care/support package, there is no reference to providing support as an ‘assessment output’. It would therefore be useful to amend the second bullet point as follows:

- *assess the level and type of service needed and agree the nature of the support services, equipment, medical care, therapy.....etc.*

Page 13

## 2.7 Assessment outputs – the Family Service Plan

Add after the sentence ‘Within a specified period after the early assessment....’

*The Family Service Plan should be provided in a format which is accessible to the parents/*

carers.

## Page 14 Consultation Questions

Question 2.3. A Family Service Plan could be particularly important when there are child protection concerns and a child has been removed from the family. There is anecdotal evidence that, in these circumstances, parents with learning difficulties in particular feel that they do not get sufficient support to enable them to better parent their child and for their child to be returned home. A Family Service Plan could be a valuable tool in these circumstances.

In general, a Family Service Plan could provide a means of ensuring that professionals and agencies do all they can to enable a disabled child's needs to be met by their birth parent and to prevent the all too common situation where disabled children drift into care because of inadequate support to their family. However, it is important that this approach (including keyworking) continues as the child grows older and it would be helpful if the Guidance stated this.

## Pages 16 and 17

### The keyworker function

Somewhere in this section, it should be specified that '*Parents/carers should be consulted on what information is passed on by the keyworker to other professionals*'.

The following sentence should also be inserted, possibly at the end of page 17:

*Agencies should ensure keyworkers have relevant information and understanding of the way other agencies work, and how to assist parents/carers to access services, information and benefits.*

It should not be assumed that an identified keyworker will already have all the relevant information and knowledge to enable them to effectively fulfil their role. Their employing organisation has a responsibility to ensure that they have the necessary knowledge and skills to do this.

## Page 18

### 3.5 Who should be the keyworker?

Ethnicity is not the only relevant issue in terms of the different circumstances which may be relevant when deciding who should be the keyworker. Keyworkers need to be sensitive to a

family's culture and religion, and also to a parent/carer's own support needs associated with physical, sensory and/or cognitive impairment.

Add to list of bullet points:

- *Does the proposed keyworker have sufficient understanding and experience of the particular family's culture and/or religion?*
- *Does the proposed keyworker have sufficient understanding and experience of the parent/carer's own support needs, particularly if the parent is disabled themselves?*

The paragraph which follows on from the bullet points should also include the sentence:

*There should be clear procedures for changing the keyworker if the family so requests.*

And the third point in the next list of bullet points should be amended as follows:

- The process for allocating *and changing* keyworkers.

Page 18

### 3.6 Sharing information about the child and family

The following sentence should be added to the first paragraph:

*The agreement of parents/carers should always be obtained before information is shared with other professionals and agencies.*

Page 22

### 4.3 Providing information for families

Although the Guidance states that, 'Within all agencies there is an increasing emphasis on user involvement in decision-making both at an individual level and service development level', this point is not developed. The emphasis is limited to provision of information – which is important but is only the first step on the road to user involvement.

Page 23

### 4.4 What kind of information helps?

Add another bullet point (after 'the rights and responsibilities of families under current

legislation')

- *Parents'/carers' entitlements to support in their own right under community care legislation, where applicable, and how to access such support*
- *Entitlements to benefits and how to access them*

Page 24

The second sentence at the top of the page should be amended to read:

For example any information given verbally at the time that disability is identified should always be supported by *information in a format which suits the parent/carer and that they can take away with them. This could include a tape recording of the relevant professional outlining the information (or a video with sign language interpretation for Deaf parents/carers).*

Page 24

#### 4.6 Practical support

Families will not just be concerned with their child's 'physical care' needs but also their cognitive, communication and emotional needs. The third bullet point should therefore be amended as follows:

- *The skills and knowledge they need in order to meet the physical care, communication, cognitive and emotional needs of their child*

Page 25

#### 4.7 Practical support for children with the most complex needs

This section needs to be expanded. It is particularly important to point out:

- the obligations placed on service providers, under the Disability Discrimination Act, to not discriminate against potential users on the grounds of their impairment.
- The importance of establishing protocols which detail both the financial and professional responsibilities in the areas of training and insurance, as well as the delivery of the additional assistance that children with complex needs require.

It would be useful, therefore, to add a couple of sentences which say something like:

*Agencies are reminded of their obligations under the Disability Discrimination Act. A senior manager should take responsibility for developing joint protocols which ensure that:*

- Appropriate training is funded and delivered*
- Adequate insurance is in place*
- Services are able to respond in an inclusive way to children with complex needs.*

The next two paragraphs do not belong under the heading 'Practical support for children with the most complex disabilities' but deal with a specific issue – i.e. the withdrawal or withholding of treatment for children with life-limiting conditions. It is suggested therefore that these two paragraphs have a separate heading along these lines.

Page 28

### 5.2 A family centred service

Add to the first bullet point:

*'...a recognition of the differing needs and expectations of families from different backgrounds and, where relevant, of the support needs of parents/carers themselves.'*

There seems to be a typographical error in the fourth bullet point. Should it be two points, i.e.

- Families and carers are effectively and appropriately engaged in the planning of service developments*
- Where feasible, services are delivered within the home.*

Page 29

### 5.3 A well planned service

Joint planning is necessary (within social services) between adults' and children's services if the needs of disabled parents and their children are to be properly responded to. Recent research highlighted both the need for, and the dearth of, joint protocols (Wates, 2002). We suggest therefore adding a bullet point to this section:

- Mechanisms are in place to enable joint planning and joint working (where appropriate) between children's and adults' services so that, where a parent is disabled, both their and their child's needs can be effectively addressed.*

Page 29

#### 5.4 A well co-ordinated service

Amend the bullet points as follows:

- Protocols have been established to enable relevant information on the needs of families to be shared between relevant professionals, *with the agreement of parents/carers*.
- There is a central bank of information for parents, which meets the needs of families from diverse backgrounds *and with different access needs*
- The assessment protocol includes assessment of the needs of the child, siblings and the family *and adult services are involved where appropriate*

Page 30

#### 5.5 An accessible service

Amend the final bullet point as follows:

- There is a clear local directory listing relevant specialist and mainstream services which families might need, *and it is made available in a format accessible to the parents/carers*.

Add the following bullet point:

- *Parents'/carers' needs for support with communication are met, for example, interpretation support or the provision of a facilitator where required.*

#### 5.6 A competent service

Penultimate bullet point: disability equality training is important for all professionals, not just in the context of 'discussing initial assessment of need', so we suggest that this last phrase is deleted.

Amend the last bullet point as follows:

- Services can demonstrate that they are responsive to individual differences in a family's racial and cultural needs, *and to any support needs of the parent/carer themselves*.

#### 5.7 Accountable service

An accountable service is one which maximises user involvement. It would therefore be appropriate to add a bullet point such as:

- *Parents/carers are involved in the planning, reviewing and monitoring of services, and also in the setting of outcomes and performance indicators.*

## References

Beresford, Bryony (1995) *Expert Opinions: a national survey of parents caring for a severely disabled child*, Joseph Rowntree Foundation/Community Care/Policy Press

Lawton, Dot (1998) *Complex Numbers: families with more than one disabled child*, Social Policy Research Unit, University of York ([Findings Ref 218](#))

Morris, Jenny (1998) *Still Missing? Disabled children and the Children Act*, The Who Cares? Trust. ([Findings Ref 378](#))

Oldman, Christine and Beresford, Bryony (1998) *Homes Unfit for Children: Housing disabled children and their families*, Bristol: Policy Press.

Sloper, Patricia et al (1999) *Getting research into practice: a case study on developing inter-agency key worker services for families with disabled children*, Social Policy Research Unit, University of York.

Wates, M (2002) *Supporting disabled adults in their parenting role*, York Publishing/Joseph Rowntree Foundation. ([Findings Ref 422](#))

Watson, D et al, 2001. *Working Together? Multi-agency working in services to disabled children with complex health care needs and their families: A literature review*, Norah Fry Research Centre, University of Bristol.