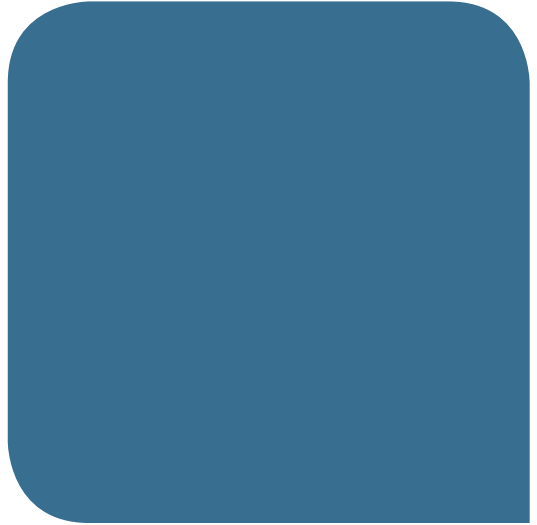


Supporting disabled parents and parents with additional support needs



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Jenny Morris and Michele Wates

First published in Great Britain in November 2006
by the Social Care Institute for Excellence

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Produced by The Policy Press
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www.policypress.org.uk

This report is available online
www.scie.org.uk

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Front cover photograph kindly supplied by Brenda Prince/Photofusion

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Acknowledgements

This knowledge review was carried out for the Social Care Institute for Excellence by Jenny Morris and Michele Wates (independent researchers), and Beth Tarleton (Norah Fry Research Centre, University of Bristol). It is the result of a collaborative partnership between the National Family and Parenting Institute, the Family Welfare Association and the Norah Fry Research Centre.

Jenny Morris led on the research literature review (Part 1), while Michele Wates carried out the practice survey (Part 2) with assistance from Beth Tarleton. Mary MacLeod (Director of the National Family and Parenting Institute), Linda Ward (Director of the Norah Fry Research Centre) and Beth Tarleton were critical readers for both the literature review and practice survey. Louise Kennedy (National Family and Parenting Institute) and Marilyn Baker (Norah Fry Research Centre) provided administrative support.

We are indebted to the following organisations, who assisted us in consulting with groups whose views are under-represented in the research literature:

- Positive Parents and Children
- CAN (a local group in Northamptonshire)
- Equalities
- Grandparents Plus
- Disabled Parents Network.

We are also indebted to those who made up our stakeholder advisory group:

Susan Aitkenhead	Department of Health
Michele Armstrong	Department of Health
Terri Balon	Disability Awareness Trainer
Ann Barker	Department of Health
Natasha Benenson	One Parent Families
Jill Bennet	CHANGE
Sarah Bower	King's College Hospital

Jabeer Butt	Race Equality Unit
Bruce Calderwood	Department for Work and Pensions
Debbie Cowley	Parenting Education and Support Forum
Rose De Paeztron	Family Welfare Association
Rhonywn Dobbing	Social Services Inspectorate, Wales
Mike Eden	Alcohol Concern
Rita Ferris-Taylor	Parentline Plus
Jenny Franks	Children's Society
Rob Greig	Department of Health
Sarah Guy	Office of the Deputy Prime Minister
Mike Hayward	Mencap
Pauline Holroyd	Adult Social Care Services, Essex
Sally Hughes	Mind
Sabina Iqbal	Deaf Parenting UK
Sue Jacob	Royal College of Midwives
John Keep	Disabled Parents Network
Craig Muir	Department of Health
Tony Newman	Barnado's
Amy Nicolas	Department of Health
Elaine Pearson-Scott	Positive Parents and Children
Stephen Pratt	Essex County Council
Gabrielle Preston	Child Poverty Action Group
Kathy Saunders	Disabled Parents Network
Mary Steen	Royal College of Midwives
Hugh Stickland	Department for Work and Pensions
Nigel Thompson	Commission for Social Care Inspection
Helen Tomkys	Department of Health
Shaun Webster	CHANGE

Thanks also to Roy Taylor, Director of Community Services, the Royal Borough of Kingston upon Thames.

We are indebted to all the parents and professionals who took part in the locality survey:

- London Borough of Greenwich, CAPE project
- Cheshire County Council and disabled parents' group
- Norfolk County Council and disabled parents' reference group

- Cardiff County Council and Vale of Glamorgan Council, Option 2 project
- Stockport Metropolitan Borough Council, Community Team for Parents with Learning Disabilities and parents' group.

Particular thanks to those who helped to organise the meetings and those who gave additional time to follow through on particular issues with Michele over the phone and by email, including Laurie A'Court, Allison Ainsworth, Richard Anderson, Rex Beach, Ali Coton, Rhoda Emlyn-Jones, Mark Hamer, Joan Inglis, Denise Monks, Debbie Morgan-Lewis, Tracy Quormby, Kathy Saunders, Bridgitte Shad, Maria Smith and Laura Sutton.

Jenny Morris
Michele Wates

Executive summary

This knowledge review on supporting disabled parents is divided into two parts: a literature review and a survey of good practice. The executive summary provides an overview of the lessons to be learnt from the knowledge review as a whole. Summaries of the literature review and good practice survey are provided at the beginning of Parts 1 and 2.

The executive summary:

- summarises the key issues arising from an analysis of the policy framework for providing services to disabled parents
- identifies implications for practice from the research review and practice survey
- discusses implications for future work.

The range of parents included in the knowledge review is deliberately broad and inclusive. It includes parents who may have additional requirements related to physical and/or sensory impairments, learning difficulties, mental health, drug and alcohol misuse-related difficulties, and those with serious illnesses, including HIV/AIDS. It includes Deaf* parents and others who may or may not identify with the term ‘disabled’.

For the purposes of this knowledge review, we will use the term ‘disabled parents’ when referring to those who are so defined in the legislation. When referring to the wider group of parents covered by this review we use the phrase ‘parents with additional support needs’. When discussing a particular group of parents, we will describe them by their particular support needs – for example, parents with mental health needs, parents with drug/alcohol problems, and so on.

* The term ‘Deaf’ (with a capital ‘D’) is used to describe someone identifies as part of the Deaf community and who uses British Sign Language (BSL). The term ‘deaf’ (with a lower case ‘d’) refers to someone with a hearing impairment who may or may not use BSL.

Key issues relating to the policy framework

Gaps within the policy framework

An analysis of the policy framework relevant to parents with additional needs shows that the framework itself does not facilitate appropriate responses from those commissioning and delivering services.

Within the adults' services policy and legislative framework:

- - Parenting roles are not treated as a central issue, with the exception of the policy framework for substance abuse.
- - Men's parenting roles and responsibilities and grandparents' roles and responsibilities have remained invisible.
- - Inter-agency relationships have been a key issue for adult social care but this focus has not included supporting disabled adults with parenting responsibilities.
- - The concern expressed by previous generations of policy makers and commentators about the relationship between children's and adults' services has, to a large extent, fallen off the agenda.

Within the children's services policy and legislative framework:

- - There is limited understanding within the family support agenda, either that steps must be taken to ensure disabled parents' access to the information and support that benefits all parents or that some disabled parents will require additional assistance to carry out parenting tasks.
- - There is very patchy recognition of the need for children's and adults' services to work together.
- - The *National service framework for children, young people and maternity services* is an exception among the current framework on children's welfare in its recognition of the role of adults' services.
- - Inter-agency relationships are a key issue within the *Every child matters* framework but the focus is almost entirely concerned with children's services in education, health and social care.
- - It would appear that the importance of adults' and children's services working together to address families' needs has, to a large extent, been lost.

With the changing structures of adults' and children's social care – including the implementation of *Every child matters*, and the completion of the White Paper on health and social care *Our health, our care, our say* – this is a key point at which to address the need for adults' and children's services to work together.

Potential for encouraging better social care practice

While failures to make the appropriate links between children's and adults' services within the current policy framework undoubtedly constitute a barrier, there are also elements within the policy framework that have the potential to encourage a more joined-up approach. These are:

- - the focus within the *Every child matters* framework on outcomes for children and the recognition that these outcomes cannot be achieved without addressing the resources, circumstances and capacity of parents and their wider family and community networks
- - the national drive towards more joined-up working across agencies in children's services, and between health and social care in adults' services, has enabled some commissioners and practitioners to work out the practicalities and experience the benefits of such coordination and cooperation.

Both the adults' and children's social care policy frameworks must also be set in the context of human rights and disability equality legislation. In particular:

- - Service providers are required to make reasonable adjustments to enable equal access to services and the Disability Equality Duty requires public authorities to proactively eliminate discriminatory practices, policies and procedures.
- - The Human Rights Act 1998 and associated case law places positive obligations on public authorities to respect private and family life.

These aspects of the policy framework also provide potential for the development of better social care practice.

Implications for practice from the literature review and practice survey

The knowledge base

Service development and knowledge-based practice are hampered by inadequacies in the knowledge base relating to the groups of parents covered in this knowledge review.

- - More research evidence is needed on the experiences of these groups of adults as parents (rather than purely as service users) and the support they need to look after their children.
- - Also required are methodologically sound evaluations of service interventions concerning all these groups of parents.
- - What evidence there is of helpful interventions and factors that promote resilience within the families covered by the knowledge review needs to be better disseminated.
- - The research literature needs to address specifically the experiences and needs of disabled fathers. There is also a need for research on the role of extended family members in caring for children and supporting disabled parents.
- - There has been insufficient attention paid to areas which appear to be crucially important to these families, for example, housing needs, the parents' role in supporting their children's education, and access to information about parenting.

Structures and procedures

Current structures and procedures mean that, all too frequently, the response to the needs of families where one or both parents are disabled or have additional support needs is crisis-driven and short-term. This can be a barrier to good outcomes for parents and children. The research literature and practice survey indicates that it is likely that the following measures would help prevent this:

- - collective ownership – across adults' and children's services, and across health, social care, housing and the non-statutory sector – of the need to provide early support

- - financial structures that make clear the benefits of providing support in time to prevent higher levels of need arising
- - clear procedures for appropriate referrals at the point of first contact
- - positive action to overcome parents' potential distrust of, and disengagement with, services
- - recognition that adults' services should have a lead role in responding to parental support needs
- - recognition that housing needs can be a significant barrier to parenting capacity and that disabled parents may need assistance in supporting their children's education
- - recognition that adults' services have a continuing role of supporting parents when children's services carry out their responsibilities under Section 47 of the Children Act 1989.

Changing cultures

A lack of knowledge and understanding about different roles and responsibilities can create tensions between adults' and children's services. The following developments have been shown (in the practice localities reviewed for this project) to reduce these tensions and bring about cultural changes:

- - key personnel – including service directors and senior managers – from adults' and children's services working together to develop protocols for joint working
- - clear strategies – jointly owned across the relevant agencies – for implementing joint protocols
- - ongoing commitment from key personnel, particularly senior managers
- - involvement of disabled parents in service development, in training and in monitoring implementation
- - joint training of all relevant personnel on an ongoing basis
- - appointment of workers whose role is to develop liaison between different services across both statutory and non-statutory sectors.

Messages from parents

Local practice is insufficiently informed by the perspective of parents on the support they need to ensure good outcomes for their children, or on what makes it possible for them to engage positively with services.

Parents consulted in the practice localities and those in the consultation groups had important messages, some of which were based on successful experiences of involvement in the development of local protocols and services.

- - Parents, including those who are currently using services, need to be involved in the development of protocols, in training, and in the monitoring of their implementation. Experienced parents who have succeeded in raising children can be a valuable resource.
- - Parents want support that strengthens their parenting role and this support should encompass the role of both fathers and mothers.
- - Children's and adults' services should recognise the role of extended family members in supporting parents and looking after children, and address their support needs.
- - Attention needs to be given – when providing information directed at parents – to parents who may need access to specialised supports, and to providing information in accessible formats.
- - Attention needs to be given to ensuring that service intervention is clearly explained, and to engaging positively with parents.

A continuum of prevention

The best practice – evident in the localities surveyed – recognised that, for disabled parents and those with additional support needs, there is a continuum of 'prevention':

- - preventing unnecessary problems from arising by addressing specialist low-level parent support needs for information, equipment and assistance
- - preventing harm to children and preventing family crises that could lead to children being placed in care

- - supporting parents whose children have been removed from home, with a view to reuniting families where possible
- - post-crisis support aimed at anticipating and preventing future difficulties.

Addressing needs at all stages of this continuum requires:

- - a change in eligibility criteria so that services can respond to lower levels of need
- - recognition that if people's parenting needs are met within the adults' social care framework, then children are less likely to be in need
- - recognition that needs relating to impairment/illness and disabling barriers must be addressed before making judgements about parenting capacity
- - bringing in children's social work expertise at points where, working in partnership with adults' social care, it is possible to prevent further problems arising
- - having clear policies and procedures for joint involvement in critical situations with the aim of building resilience and the ability to cope in the future
- - joint commissioning and joint working to provide flexible, ongoing support where required
- - anticipating changes in needs in relation to both impairment/illness and family circumstances.

Good practice recognises that parents with additional support needs need access to mainstream parenting information and support, and that for this to happen, barriers to access (both physical and attitudinal) need to be removed. At the same time, it is essential that any additional and specialist support needs that disabled parents may have should be addressed in time to prevent unnecessary difficulties arising.

Implications of the knowledge review for future work

National and local frameworks

The literature review and practice survey demonstrate the need for mechanisms to encourage agencies to work together to:

- ensure early responses which prevent problems arising
- - provide support that strengthens the parenting role
- - provide family-focused support (including recognising the role of the extended family).

The relationship between national direction setting and local development of policies and protocols was discussed both in the locality meetings (see the practice survey) and the knowledge review stakeholder group.

There is an argument that local agencies prefer to develop their own protocols for inter- and intra-agency procedures. The good practice examples examined suggest that local protocols arise out of particular contexts, address specific difficulties that have arisen, and, at the same time, bring about the commitment of all relevant parties to following the procedures agreed. Such protocols have been found useful in agreeing procedures for:

- - initial contact and referral
- - multi-agency working
- - addressing specific gaps that emerge in inter-agency liaison, for example between adult specialist teams and housing authorities
- addressing specific gaps that emerge in communication between services and parents, for example, home–school liaison and hospital–parent liaison.

Local protocols have also proved useful in agreeing:

- guidelines for parents about the services available and how to access them
- - up-to-date reference information about contacts and resources.

However, although there is clear value in local agencies responding to specific local issues and relationships, there is also value in making examples of local protocols and procedures which may be of wider interest and relevance available nationally.

In addition, there was broad agreement – in both the localities and the stakeholder group – that some form of national direction is needed to:

- indicate the importance of this issue
- - encourage good practice in all parts of the country
- - enable the lessons learnt from the development of local protocols to be applied nationally
- - provide specific information and resources.

Drivers and incentives to better practice

There is currently a lack of national drivers and incentives to encourage better practice in working with disabled parents and their children. Indeed, some of the current drivers may militate against good practice. For example, targets to carry out core assessments within a specified time period may not allow for the additional time required to fully assess the capacities of a parent with learning difficulties.

Five potential drivers and incentives can be identified which could promote good outcomes for disabled parents and their children:

- - **National and local performance indicators.** The current framework – particularly that for local public service agreements – provides an opportunity to encourage good practice in supporting disabled people to fulfil their parenting role and responsibilities. However, further evidence is generally required on what kind of indicators would measure outcomes (see also 3.3 below). This work could be usefully linked to the Department for Work and Pension's work on outcomes and indicators of disability equality (as part of the implementation of the Disability Equality Duty).
- - **The role of inspection.** The new framework for the inspection of children's services will use the outcomes laid down in the *Every child matters* framework to guide the methodology of inspection. The Commission for Social Care Inspection (CSCI) has similarly proposed a clear outcomes framework for adult social care. This

framework includes family roles and responsibilities and proposes that support to carry out parenting roles is one of the inputs to be measured. It would be useful if Ofsted and the CSCI developed a joint methodology for children's services and adults' social care inspections which would enable proper attention to the need for adults' and children's services to work together to improve outcomes for families where at least one parent is disabled or experiences long-term illness or substance abuse problems.

- - **National policies which promote working across local organisational boundaries.** Structures such as local strategic partnerships and mechanisms such as local area agreements could provide a framework of organisational and financial incentives to joint working across health, social care, education, housing and the voluntary and community sector.

The potential role for individual budgets in promoting a more comprehensive approach to support needs should also be examined.

- - **Engaging with practitioners.** Initiatives that engage directly with practitioners to promote and encourage good practice can also be a driver for change. There is already a Parental Mental Health and Child Welfare Network, and a practitioner network concerning parents with learning difficulties will be established later in 2006. Such networks offer key opportunities to learn from, promote and disseminate good practice.
- - **The role of parents in promoting good practice.** Many good practice initiatives have developed in partnership with disabled parents and some have been the direct result of pressure from disabled parents' groups. Parents themselves can therefore be an important driver for good practice and their involvement needs to be encouraged and resourced.

Gaps in the knowledge base for practice

There is a clear need to encourage:

- - research on the needs and circumstances of families where one or both parents is disabled or has additional support needs. Such research

should address the gaps identified in the literature review. That is, needs associated with parenting (rather than the experiences of using services); the roles of fathers and the extended family; parents' experiences of housing; supporting children's education; access to information and other hitherto unexamined factors

- rigorous evaluations of service interventions
- - dissemination of the knowledge base for practice.

Conclusion

In conclusion, this knowledge review has demonstrated that there is a need for:

- - materials to promote good practice in supporting disabled parents
- - research to address significant gaps in what is known about the needs and experiences of parents with additional support needs
- - the development of appropriate indicators for assessing how well families with a disabled parent are supported
- - an exploration of the potential of mechanisms such as local public service agreements, local strategic partnerships, local area agreements and individual budgets for enabling social care commissioners and providers to better meet the support needs of disabled parents
- - the promotion of practitioner networks to encourage good practice
- - the involvement of disabled parents in all activities relating to improving support to families.

Summary

This knowledge review is about parents with physical and/or sensory impairments, learning difficulties, mental health problems, long-term illnesses such as HIV/AIDS, and drug or alcohol problems. The main focus of the knowledge review is on social care, but integral to this are the relationships between social care and health, housing and education.

The policy and legislative framework

- - There are clear entitlements within the legislative framework for adult social care to support disabled parents.
- - However, parenting roles are not treated as a central issue within the adult social care policy framework. Men's parenting roles and responsibilities are particularly unrecognised.
- - Within the *Every child matters* policy and legislative framework there is very little recognition of the entitlements that parents have under adult social care legislation for support in their parenting role.
- - While the children's and adults' policy and legislative frameworks place great emphasis on inter-agency cooperation, there is only limited recognition of the need for children's and adults' services to work together.

The needs and experiences of disabled parents

There is an inadequate knowledge base to inform policy and service development:

- - There is incomplete statistical information about the numbers of disabled parents and some of the statistical information that is available is confusing.
- - Most of the research evidence concerns parents who are in touch with children's social services and/or specialist adults' services, and most of the research concerns their experiences of services. There is very little research on the experiences of disabled parents generally.
- - The literature often fails to differentiate but appears to be concerned with the experiences of mothers only. The specific support needs and experiences of fathers generally remain invisible.

- - There is very little research about the role or needs of extended family members who are supporting disabled parents.
- - There are very few methodologically rigorous evaluations of service interventions involving these groups of parents.

Disabled parents appear to be at a disproportionate risk of experiencing socio-economic disadvantages. In particular:

- - Disabled parents are more likely to be unemployed and to be living in low income households. At the same time, they have additional costs associated with impairment and/or illness which are not adequately met by disability benefits.
- - Poor housing and a lack of housing choice is correlated with impairment and/or illness.
- - Families living in the poorest neighbourhoods are more likely to experience poor physical and mental health and long-term illness and disability. The effects of poverty and material deprivation are compounded by the effects of a poor neighbourhood environment.
- - Some disabled parents report negative attitudes (or fear of negative attitudes) towards them as parents and/or towards their support needs and this can act as a deterrent to approaching services and/or disclosing support needs.
- - Social isolation – created by poverty, discrimination and/or inaccessible communication methods – means that parents miss out on informal and formal sources of information.

While there is insufficient research on support needs from the point of view of parents, there is evidence that they include:

- - A range of support needs during pregnancy and childbirth. For example:
 - > maternity units which are physically suitable for parents with mobility impairments
 - > accessible information about ante-natal care and childbirth
 - > information about the effects of medication
 - > addiction treatment services and early access to HIV diagnosis and treatment.

- - Assistance with looking after new-born babies. This can include:
 - > the provision of appropriate equipment
 - > mother and baby units for women experiencing post-natal psychosis
 - > sensitive personal assistance
 - > support to bond with a baby placed in a special care baby unit because of opiate withdrawal symptoms.
- - Support with the everyday tasks of parenting. This may include:
 - > ongoing personal assistance to help parents with physical impairments to look after their children
 - > support for parents with learning disabilities to help them learn to respond to their children and/or ongoing support
 - > assistance to support their children's education.

The following issues are highlighted in the research evidence about support needs:

- - Fluctuations in impairment and/or illness can create fluctuations in support needs.
- - Experiences such as unemployment, poor housing, domestic violence and family conflict can have as significant an impact as impairment, illness or substance abuse. Parents may, for example, have pressing needs for information, advice and advocacy in respect of housing, benefits and debt.
- - Although there is evidence that Deaf children born to Deaf parents do better academically, are more socially mature and have more positive self-esteem than Deaf children born to hearing parents, the research literature does not examine whether there are other positive experiences associated with parental disability.
- - Parents are often aware of the difficulties their children may experience because of parental needs and circumstances and appreciate support services which help to make up for some of these difficulties.
- - The role of the extended family and informal community networks is often important for these groups of parents.

Research indicates that parents in general value support which is easy to access, is not stigmatising, and which creates and enhances informal support networks. They want:

- - practical and professional help
- - their views to be taken seriously and to be treated as partners by professionals and service providers
- - services to be supportive, respectful and considerate
- - to feel in control in dealing with parenting problems
- - information to help solve problems themselves and then, if necessary, specialist advice
- - help provided in time to avoid problems arising rather than in response to a crisis.

In terms of what we know about disabled parents' experiences, the (mainly qualitative) research literature indicates that they value:

- - Flexible, practical support. This includes support that meets the personal assistance needs associated with physical impairment, practical support with getting children to and from school, assistance with getting children into a routine, and so on. Direct payments have been particularly useful as a way of enabling parents to have more choice and control over the way support is provided. So too have voluntary sector services which provide support tailored to each family's circumstances. These services have proved particularly helpful for parents with mental health problems and those with drug and/or alcohol problems.
- - Services which meet a range of support needs. This includes information, advice and advocacy, and counselling. Parents particularly appreciate services which enable them to gain support from other parents in similar situations. This range of services is more often found within the voluntary sector than the statutory sector.
- - Services that enable them to have a break from caring for their children. Such services are particularly likely to be valued by parents who are ill, in pain and/or who experience high levels of stress, and by those who have few informal sources of support to draw on.
- - 'Ordinary' experiences for their children. Parents do not want their children to be stigmatised because of their contact with services.
- - Universal services as opposed to specialist services. Universal services do not have the stigma attached to statutory social services. However, sometimes the particular needs of parents mean that they appreciate services that have specialist expertise.

- - Services which, in meeting their access needs, enable them to support their children's education.

Disabled parents report a number of difficulties in their contact with statutory services:

- - disputes between children's and adults' services about assessment and funding responsibilities
- - failures of communication and coordination between different services and particular difficulties when a parent falls into more than one service user group
- - high eligibility thresholds for both children's and adults' services which mean that support to prevent problems developing cannot be accessed
- - inadequate early access to independent advocacy services
- - insensitive or inadequate responses to particular cultural needs
- - a failure to acknowledge or respond to the support needs of extended family members who are supporting a disabled parent.

The experiences of services and practitioners:

- - Sometimes people working in adults' services lack confidence and experience in addressing the needs of parents and report particular difficulties when parents' needs cross specialist service boundaries.
- - A fragmented approach to services can create unintended costs. For example, a failure to provide adaptations and equipment speedily can create greater expenditure on health and social care. Similarly, a high eligibility threshold for adults' services can create expenditure for children's services when parents experience problems.
- - Local factors are sometimes a more important influence on practice than the statutory framework. For example, eligibility criteria based on a person's intelligence quotient is unlikely to be lawful, but shortage of resources means that some learning disability teams operate such a policy.
- - There are problems with communication and coordination across children's and adults' services. These are associated with a lack of knowledge and understanding of respective responsibilities, language

and culture and compounded by the high eligibility criteria operated by each service.

- - Professionals working in universal services may lack the relevant skills or experience to deal with specific support needs and feel that they and their service users would benefit from close working relationships with specialist services. This is not always available, however, sometimes because of high eligibility thresholds.
- - By the time a child's needs meet the high eligibility thresholds operated by children and families' services, there are likely to be significant problems and in these circumstances statutory responsibilities to protect children can make it difficult to work in partnership with parents.
- - Children's social services often struggle to provide the kind of flexible, practical support valued by parents.
- - While most families in contact with children's social services have a range of support needs, this is not always recognised or responded to. Practitioners report that they need access to specialist support and information – for example, information about mental health needs or substance abuse – but this is not always available.
- - Most of the focus within children's services is on the role and responsibilities of mothers, with insufficient attention paid to supporting fathers and to the role of the extended family.

Progress in overcoming the barriers:

- - The needs of disabled parents have started to be recognised in early interventions and preventative services initiatives, for example in some Sure Start and Parenting Fund projects.
- - Good practice in statutory services is developing but this is usually happening in isolation at a local level and sometimes even within a locality with little reference to other local services.
- - There has been an increase in the development of protocols for partnership working between children's and adults' services and across health and social services (and sometimes housing, education and the voluntary sector).
- - Some services have developed assessment tools for working with people with learning difficulties.

- - There is increasing recognition among specialist substance abuse services of the needs of parents with drug or alcohol problems.
- - There have been important initiatives within the voluntary sector, valued by both parents and workers in the statutory sector.

Introduction

Areas of policy and practice covered in this knowledge review

This knowledge review has been carried out for the Social Care Institute for Excellence (SCIE). Its primary focus is on social care in both the statutory and non-statutory sectors. Integral to this focus are the relationships between social care agencies and health, education and other agencies. It is predominantly concerned with how policies and practice address the needs of parents, and while the needs, experiences and rights of children are important, they are not the central focus of this literature review. The policy and legislative framework for children's services is, however, examined in Chapter 2. We have also summarised some of the research evidence concerning children's experiences in Chapter 3 and children's services' experiences of addressing parental support needs are included in Chapter 4. Finally, we consulted with a group of children of disabled parents, and their views are incorporated at relevant points in the knowledge review.

The policies and practice concerned with child protection and those concerned with young carers are part of the context of this knowledge review and are both sensitive areas. This literature review does not present any particular view of, for example, recent controversies concerning parents with learning difficulties, or of the historic tension between the young carers' lobby and the disability movement. Instead, it takes a balanced view of what the available research tells us about parents' support needs and their experiences in getting those needs met.

Parents covered by this knowledge review

Attempts to name and categorise groups of people who might need or use services usually encounter difficulties with meaning, precision, inclusion and exclusion. This is especially true where people experience discrimination and prejudice.

SCIE's commissioning brief set out a broad definition of the term 'disabled parent,' to include parents with physical and/or sensory impairments, learning difficulties, mental health problems, HIV/AIDS, and

drug and/or alcohol problems. Many of the parents who fall into one (or more) of these groups will not come into contact with either adults' or children's social care services, and for some groups most people will have no contact with statutory services in their role as parents. However, almost all of the current research literature concerns parents who *are* in contact with statutory and/or voluntary sector adults' or children's social care services.

The knowledge review is concerned with England, Wales and Northern Ireland as these are the parts of the United Kingdom (UK) in which SCIE has a role.

The terms 'disabled parents' and 'parents with additional support needs'

The stakeholder group advising this knowledge review was made up of representatives from the wide range of statutory and voluntary sector organisations concerned with providing support to, or representing, families with Deaf* parents, physical and/or sensory impairments, learning difficulties, mental health, drug and alcohol misuse-related difficulties and/or those with serious illnesses including HIV/AIDS. The group was asked whether the term 'disabled parents' or 'parents with additional support needs' was the most appropriate. Most felt that the former was more appropriate. This was for two main reasons:

- - 'Additional support needs' is too broad a term as it could refer to, for example, parents with low birth weight babies, lone parents, homeless parents and so on.
- - The term 'disabled parents' places the focus on the barriers created by society rather than focusing on the individual characteristics of parents. It is therefore the term used by Disabled Parents Network and others who adopt the social model of disability.

* The term 'Deaf' (with a capital 'D') is used to describe someone identifies as part of the Deaf community and who uses British Sign Language (BSL). The term 'deaf' (with a lower case 'd') refers to someone with a hearing impairment who may or may not use BSL.

Those who felt that the term ‘parents with additional support needs’ might be more appropriate argued that:

- - The term ‘disabled parents’ did not include parents with drug and/or alcohol problems.
- - The term ‘additional support needs’ is used within the *Every child matters* framework to refer to ‘vulnerable children’ and it would therefore be consistent to use the same term for parents.

There are difficulties with each term: the term ‘disabled person’ has a legal definition (within both anti-discrimination and community care legislation, as discussed in Chapter 2) and not all the parents covered by this knowledge review are so defined. On the other hand ‘additional support needs’ is too broad a term and encourages a medical model approach to people’s needs. There is the additional complication that many people move into and between different categories over time. We discuss ‘overlapping populations’ in Chapter 1 but people may also start off with one ‘label’ and set of needs, and then acquire another – either temporarily or permanently. A person with mental health problems, for example, may acquire a hearing impairment as a result of long-term use of medication. Similarly a person experiencing high levels of pain associated with a physical condition may acquire an addiction.

For the purposes of this knowledge review, we use the term ‘disabled parents’ when referring to those so defined in legislation. When referring to the wider group of parents covered by this review we use the phrase ‘parents with additional support needs’. When discussing a particular group, we describe parents by their particular support needs – for example, parents with mental health needs, parents with drug and/or alcohol problems, and so on.

It should be recognised that many, and perhaps a majority, of parents covered by this knowledge review, would not identify with the term ‘disabled’.

The terms ‘learning disabilities’ and ‘learning difficulties’

Many people who are described as having a ‘learning disability’ prefer the term ‘people with learning difficulties’. They use this term to mean

‘people who since they were a child had a real difficulty in learning many things. We do not mean people who just have a specific difficulty in learning, for example, people who only have difficulty with reading which is sometimes called dyslexia’.¹ One of the objections that people have to the term ‘learning disability’ is that it can be taken to mean that they are not able to learn. Such an assumption has particular implications for parents who may be required to prove that they can look after their children.

On the other hand, the term ‘learning disabilities’ is used within the statutory framework for social care support while the term ‘learning difficulties’ is used within the special educational needs statutory framework: the two definitions are not the same. However, it is clear that when people define themselves as ‘people with learning difficulties’ they mean people who, within the statutory framework, would be referred to as ‘people with learning disabilities’. Therefore, when referring to the statutory framework for supporting people with learning difficulties, the term ‘learning disabilities’ is sometimes used in this knowledge review. It is also used when quoting authors who themselves use the term. However, generally, we use the term ‘learning difficulties’.

How the literature review was carried out

There are a number of literature reviews, carried out in recent years, concerning all but one of the groups of parents covered by this knowledge review. The reviews concerned are:

- - *Children’s needs – parenting capacity: The impact of parental mental illness, problem alcohol and drug use, and domestic violence on children’s development.*²
- - *Disabled parents: Examining research assumptions.*³
- - *Parental problem drinking and its impact on children.*⁴
- - *Parental drug misuse: A review of impact and intervention studies.*⁵
- - *Parental mental health problems: Messages from research, policy and practice.*⁶
- - *What works for parents with learning disabilities.*⁷

The following research briefings – which summarise the policy and research literature – are published by the Social Care Institute for Excellence:

- - *Helping parents with learning disabilities in their role as parents.*⁸
- - *Helping parents with physical or sensory impairments in their role as parents.*⁹
- - *Parenting capacity and substance misuse.*¹⁰
- - *The health and well-being of young carers.*¹¹

In addition, a SCIE project team conducted a literature search when writing the project brief and this was made available to us. The Norah Fry Research Centre, part of our consortium for the knowledge review, carried out a literature search about parents with learning difficulties for their own research project, and this was also made available.

Together these existing resources provided a fairly comprehensive list of the relevant literature and they have been used to identify relevant research. The reviews themselves have also been used when summarising what we know both about the needs and circumstances of parents and their children, and the policy and practice issues.

In addition, searches were undertaken for:

- - research literature concerning parents with HIV/AIDS
- - research literature published since the reviews listed above.

These two literature searches were made using the following databases:

- - PsycINFO
- - PubMed
- - the Education Resources Information Centre (ERIC)
- - British Library Integrated Catalogue (which now substitutes for SIGLE)
- - Evidence Bank (Research in Practice)
- - CareKnowledge
- - Social Care Online.

A Google search was also performed, as well as a search of the Joseph Rowntree Foundation's website. We excluded research literature which solely related to the medical and health care implications of medical conditions/impairments for parenting. We also excluded literature relating to developing countries.

Particular attention was paid to research that:

- - included a longitudinal study
- - included a large-scale survey
- - had been positively critically appraised
- - rigorously evaluated an intervention or interventions
- - had a particular focus on parents' and children's experiences.

Much of the material identified in these two literature searches is 'grey literature', that is sources such as internal reports, government documents, conference proceedings, theses, newsletters and so on. We have referred to recent examples published since the literature reviews listed above and also to material concerning parents with HIV/AIDS. We have also identified when the source cited is grey literature.

An attempt has also been made to make links with research literature that is relevant to disabled parents, but which comes at the issues from different angles, such as what works in parent support generally, what works for children, and the role of kinship care.

Finally, we held meetings with five groups, who have experiences which are under-represented in the research literature. These were:

- - parents with HIV/AIDS
- - parents with drug and/or alcohol problems
- - black and minority ethnic parents
- - grandparents
- - children of disabled parents, who have not been identified as young carers (most of the research literature concerning children of disabled parents is of those who are in receipt of services for young carers).

Experiences from these consultative groups have been used to inform the knowledge review, in particular Chapter 3. Appendix 1 provides information about how the consultation groups were recruited and how the discussions were organised.

What we know about the numbers of parents covered by the remit of this knowledge review

Unsurprisingly there is no one source of information about all the different groups of parents covered by this knowledge review. Neither is there adequate statistical information about any of the groups. Moreover, some needs are not static or permanent and many people experience more than one type of difficulty.

1.1 Disabled parents

The main sources of information about numbers of disabled parents are the *Labour force survey** and the *Families and children study*, both commissioned by the Department for Work and Pensions. They both cover England, Scotland and Wales.

Since 2004, the *Labour force survey* has used the definition of disabled person contained in the Disability Discrimination Act 1995: that is, anyone with a long-term health problem or disability which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities. Using this definition, about 12 per cent (1.7 million) of Britain's 14.1 million parents are disabled¹² and 1.1 million households with dependent children have at least one disabled parent.¹³

* Prior to 2004, the *Labour force survey* combined two categories – 'Current Disability Discrimination Act disabled' and 'Work limiting disabled' – to give a total of 'long-term disabled'. It was this combined category which was used to extract statistics relating to disabled parents presented in a paper to Her Majesty's Treasury in 2003 that have subsequently been quoted in the literature on disabled parents. These 2003 statistics identify a larger number of disabled parents (because they include people who are 'work limiting disabled') than the statistics presented here in this paper (which only include people who are 'Disability Discrimination Act disabled').

The *Families and children study* asks respondents about 'long-standing illness or disability which limits their ability to go about daily activities'. Among mothers who identified with this definition, the most commonly cited health problems or disabilities (more than one could be recorded) were: problems with arms, legs, hands, feet, neck or back including arthritis or rheumatism (47 per cent); depression or other mental illness (26 per cent); and chest or breathing-related problems such as asthma and bronchitis (17 per cent). One in five were recorded as 'Other'.¹⁴

1.2 Parents with learning difficulties

A recent survey of people with learning difficulties in England found that, in a sample of almost 3,000 people, seven per cent had children, although this included children who were now adults.¹⁵ This survey also found that only just over half of the parents were currently looking after their children.

Previous estimates of the numbers of parents with learning difficulties vary between 26,000 and 250,000 (see Booth and Booth, 2004, for a discussion of the various sources). This range in estimates indicates that it is important to be cautious about using the term. A wide-ranging review of 'what works' for parents with learning disabilities states that while 2.2 per cent of the population is recognised as having a learning disability (varying from 'mild' to 'profound'), 'about 6.7 per cent of the population falls within the borderline of possibly having a learning disability'. In addition, individuals may exhibit different ability levels across the components of IQ and other tests used. The authors conclude 'in reality there is no clear demarcation between parents who have learning disabilities and those who do not'.¹⁶

Whatever the total number, there has been an increase in the numbers of parents with learning difficulties in contact with health and social care services.^{17,18} As more people with learning difficulties lead 'ordinary lives', it is not unexpected that more of them will become parents. Moreover, in at least one growing minority ethnic community, it is generally expected that people with learning difficulties will marry and have children. Because of their support needs this is leading to increased referrals to both adults' and children's services.^{19,20}

1.3 Parents with mental health support needs

It has been estimated that – at any one time – just under four per cent of all parents with dependent children in the UK have moderate to severe mental health problems. This amounts to approximately 1.7 million adults and 2.5 million children.²¹ However, this estimate does not tally with current *Labour force survey* and *Family and children study* figures, which record a total of 1.7 million parents in England, Wales and Scotland with a long-term health problem or disability, 26 per cent of whom are parents with mental health problems. This would imply that there is a total of about 450,000 parents with mental health problems in Britain.

Whatever the true number of parents with mental health problems, they make up a significant group of both individuals using adult mental health services and of families in contact with children's social services. A survey of adults with mental health problems in Britain carried out in 2000 found that 31 per cent of adults with mental health problems were living in households made up of a couple and children. Seven per cent lived in lone-parent households.²²

Falkov summarises a number of studies which indicate that 20–25 per cent of people using adult mental health services are parents.²³ The percentage varies from one study of women with severe mental illnesses which found that nine per cent were the primary caregiver for a child,²⁴ to a study of women in contact with community mental health services which found that 59 per cent were mothers.²⁵ Children of parents with mental health problems make up between a third and a half of all children receiving services from young carers' projects, while local service audits indicate that 'parental mental health concerns are likely to be a pressing problem in about a quarter of new referrals to social services, with higher proportions for children involved in protection enquiries or those newly looked after by the local authority'.²⁶

There is some indication that there may be an increase in the numbers of people with psychotic disorders who become parents, although it is difficult to judge the size of this increase as there has been a historical under-recognition within psychiatric services of the proportion of patients (particularly men) who are parents. Nevertheless, 'with the advent of community care, atypical antipsychotics and changing attitudes more patients may be having children'.²⁷

1.4 Parents with drug and/or alcohol dependency

Drawing on existing research, the Prime Minister's Strategy Unit estimates that between 780,000 and 1.3 million children in the UK are affected by a parent with alcohol problems.²⁸ The definition of 'problem drinking' is contentious but the Strategy Unit report used that of double the daily recommended limit.

There are estimated to be between 200,000 and 300,000 children in England and Wales (data for Northern Ireland are not available) who have parents who misuse drugs.²⁹ This represents about two to three per cent of children under the age of 16 but only about a third of fathers and two-thirds of mothers are still living with their children (most of the children are living with other relatives). An estimated one per cent of babies are born each year to women with drug problems, and a similar number of children are born to women with alcohol problems. Most maternity units have reported an increase in the number of pregnant women with drug problems over the last five years.³⁰

A significant minority of parents in contact with children and families social services have problems with alcohol and/or drugs. One study analysed 290 cases allocated to social workers for long-term work in four London boroughs and found that 'a third of these involved parental substance misuse'.³¹ The Advisory Council on the Misuse of Drugs found that, on average, parental problem drug and/or alcohol use featured in a quarter of cases of children on child protection registers.³²

1.5 Parents with HIV/AIDS

There are no statistics recording the number of parents with HIV/AIDS or number of children whose parents have a diagnosis of HIV/AIDS. The only relevant information is derived from two sources: statistics on the number of children born to HIV-infected women in the UK (which do not include the significant proportion of mothers with HIV/AIDS whose children were born abroad); and statistics on the number of adults with HIV/AIDS who acquired it through heterosexual intercourse (which do not distinguish those who are parents).

The Royal College of Obstetricians and Gynaecologists has been collecting statistics on the numbers of pregnant HIV-infected women in the UK and Ireland since 1989. By the end of 2004, a total of 6,286

children had been born to HIV-infected mothers and were resident in the UK.³³ The numbers of children being born to HIV-infected mothers have increased substantially since 1997, with six times as many reported in 2003 as in 1997.³⁴ The prevalence of HIV among women giving birth in London was 0.45 per cent in 2003 and 0.16 per cent in England,³⁵ but the numbers outside London are rising.³⁶ Most children born to HIV-diagnosed women are born uninfected but about one in four born to undiagnosed women are HIV positive.

At the end of 2004 an estimated 58,300 adults aged over 15 were living with HIV in the UK, 34 per cent of whom were unaware of their infection.³⁷ About 27,000 had acquired their infection through heterosexual intercourse and, of these, just under two-thirds are black African. The majority of this group live in London and acquired the infection in sub-Saharan Africa or South Eastern Africa, particularly Zimbabwe.³⁸ Although the majority of heterosexuals with HIV/AIDS are black Africans it is important to note that they make up a very small percentage of all black Africans. For example, in 2004, 4.4 per cent of black Africans aged 16–44 in England, Wales and Northern Ireland were living with diagnosed HIV infections (compared to 0.3 per cent of black Caribbeans, 0.03 per cent of Indian/ Pakistani/ Bangladeshis and 0.07 per cent of those of white ethnicity).³⁹ Only 2.2 per cent of women from sub-Saharan Africa who gave birth in 2004 were HIV positive.⁴⁰

1.6 Overlapping populations

While health and social care services divide people into the groups mentioned above, many individuals have experiences which mean they straddle more than one 'service user' group.

Within substance misuse and mental health services, there is a recognition that many service users have a dual diagnosis of both drug and/or alcohol problems and mental illness. A multi-centre study of substance misuse and mental illness found that 75 per cent of users of drugs services and 85 per cent of users of alcohol services experienced mental health problems; 44 per cent of patients of Community Mental Health Teams in the same study reported drug use and/or harmful alcohol use in the preceding 12 months.⁴¹ There is a particularly high correlation between post-traumatic stress disorder among women and substance misuse (ranging between 30 and 59 per cent). This is

presumably related to the prevalence of childhood physical and sexual abuse among women with drug misuse problems – estimated at between 50 and 99 per cent.⁴²

Disability and illness are also correlated with mental health problems. For example, a systematic review of inequalities in mental health found that people who had two or more physical illnesses were six times more likely to develop a ‘disabling mental disorder’ than those who did not.⁴³ Physical illness is a stronger marker for mental ill health than any other factor (including socio-economic status and major adverse life events).

A review of the literature relating to people with physical impairments and mental health support needs highlighted evidence that:

- - people with mental health support needs are more likely to acquire physical impairments
- - people with physical impairments are more likely to develop mental health problems.⁴⁴

There is also considerable evidence of a higher risk of mental health problems among people who are born deaf. Deaf adults appear to experience the same rates of psychoses as the general population, but higher rates of other forms of mental illness.⁴⁵

Finally, before moving on to Chapter 2, where we look at the policy and legislative framework, it is worth referring to government estimates of the number of children who are likely to be in need of support because of their and their families’ needs and circumstances. The Green Paper *Every child matters* estimates that there are three to four million vulnerable children and, of these, 300,000–400,000 are ‘children in need’. The latter term refers to those children who would qualify for Children Act 1989 services because, without such support, they are unlikely to achieve a ‘reasonable standard’ of health or development, or because they are disabled. It is, however, unclear what the definition of ‘vulnerable’ is, although the Social Exclusion Unit says that 3.6 million children are living in low income households and are at risk of social exclusion.⁴⁶ Guidance on the *Common assessment framework* refers to ‘children with additional needs’ as the 20–30 per cent of children who require extra support from education, health or social services at some point in their childhood to help them achieve the five *Every child matters* outcomes.⁴⁷ It is likely that many of these children and perhaps a majority of ‘children

in need' are living in families affected by one or more of the additional support needs covered by this knowledge review.

The policy and legislative framework

This chapter discusses the various policies, legislation and guidance that make up the framework for the provision of support to families covered by this knowledge review.

The Disabled Parents Network has recently published a comprehensive information pack setting out what entitlements disabled parents have under current legislation.⁴⁸ A detailed review of the legislation has also recently been published by Barnardo's.⁴⁹ This chapter does not attempt to replicate either of these publications and for a detailed account of the relevant legislation the reader is advised to refer to them. Instead, the focus of this review is on identifying the potential of and the gaps in the policy and legislative framework.

This chapter is concerned with the policy and legislative framework rather than how it is put into practice. Commentary is therefore limited to policy documents and legislation. The actual implementation of policy and legislation is discussed in Chapter 4.

The references given in this chapter are mainly to the English versions of legislation, guidance and policy, for example, the Children Act 1989 (in Northern Ireland, the equivalent is the Children (Northern Ireland) Order 1995). Where there are any differences in legislation or in the policy framework for Northern Ireland or Wales, this is identified.

2.1 Documents that make up the policy and legislative framework

Government policy is set out in documents such as *Every child matters: Change for children*, White Papers such as *Our health, our care, our say* and national service frameworks such as the *National service framework for mental health*.

The legal framework consists of:

- - Statutes (Acts of Parliament in England and Wales or Orders in Council in Northern Ireland) which set out the law (for example, the Children Acts 1989 and 2004, the Children (Northern Ireland)

Order 1995 and the Disability Discrimination Act 1995). Statutes say what must be done.

- - Regulations and orders, which provide more detail about how statutes should be interpreted and implemented (for example, the Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2004) and which have the same status as statutes. Therefore, regulations also say what must be done.
- - Codes of practice, which public bodies are required to have regard to (for example, *Code of practice – rights of access to goods, facilities, services and premises in part 3 of the Disability Discrimination Act 1995*). Courts expect public authorities to follow codes of practice unless they can show that some flexibility is required to meet the needs of a particular case.
- - Policy guidance issued under Section 7 of the Local Authority Social Services Act 1970. Local authorities carrying out social services functions are expected to follow guidance issued under this Act (for example, *Framework for the assessment of children in need and their families*) unless they can show (if necessary in a court) that they have good reason not to. This type of guidance is also referred to as statutory guidance.
- - Practice guidance which advises local authorities on fulfilling their statutory duties but which need not be strictly followed (for example, *Assessing children in need and their families: practice guidance*). However, in the event of a legal challenge, courts will have regard to any relevant practice guidance.
- - Case law (judicial reviews) sets precedents for how legislation and guidance should be interpreted.

2.2 Definitions within the policy and legal framework

In terms of the current policy and legal framework, this knowledge review is concerned with two, overlapping, groups of parents.

- a. -Disabled people – that is, people who come under the definitions of a disabled person used by community care legislation and/or the Disability Discrimination Acts 1995 and 2005. These definitions are as follows:

The definition used in community care legislation is that set down in the National Assistance Act 1948, section 29: a person who is ‘blind, deaf or dumb or who suffers from mental disorder of any description, and other persons aged eighteen or over who are substantially and permanently handicapped by illness, injury or congenital deformity’. Under Disability Discrimination Act 1995, section 1: a person who ‘has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities’.

- b. -A larger group of parents who have support needs that are in addition to the general population of parents, some (but not all) of whom may come within one or both of the above two definitions of disabled person. Those who do not come within either definition of disabled person include many people with mental health problems whose difficulties do not meet the ‘substantial’ and/or ‘permanent/long-term’ criteria in the above two definitions and people who abuse drugs and/or alcohol (however, some of these people may meet the definition of disabled person because of impairment/illness associated with substance abuse).

In terms of the current policy and legislative framework concerning children of either disabled parents or parents with additional support needs, there are four (overlapping) groups that can be identified.

- a. -Children in need, as defined by the Children Act 1989 (in Northern Ireland, the equivalent is the Children (Northern Ireland) Order 1995). A child is in need if:
 - he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part
 - his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services or
 - he is disabled.^{*, 50}

* The definition of disabled child used by the Children Act 1989 is the definition in the National Assistance Act 1948.

- b. -Children who are experiencing, or who are at risk of experiencing, significant harm, and where the children's services authority then has a duty to make 'such enquiries as they consider necessary to enable them to decide whether they should take any action to safeguard or promote the child's welfare'.⁵¹
- c. -Children who take on a caring role to the extent that they meet the definition of carer within carers' legislation,⁵² that is, 'someone who provides or intends to provide a substantial amount of care on a regular basis' to a person who has been assessed as needing a service under the NHS and Community Care Act 1990 or the Chronically Sick and Disabled Persons Act 1970 (in Northern Ireland, the Chronically Sick and Disabled Persons (NI) Act 1978).
- d. -Disabled children*, who are not only covered by obligations towards children in need (as set out in the Children Act 1989 and accompanying guidance) but may also meet the definitions of disabled person as laid down by the Disability Discrimination Act 1995 and the Chronically Sick and Disabled Persons Act 1970 (which was extended to children by the Children Act 1989/Children (Northern Ireland) Order 1995). They may also have special educational needs, as defined by the *Special educational needs code of practice 2001 (England and Wales)* or the *Code of practice on the identification and assessment of special educational needs 1998 (Northern Ireland)*.

2.3 Disability Discrimination Acts 1995 and 2005

An important part of the legislative framework is the protection from discrimination afforded by the Disability Discrimination Act 1995 and the duty placed on public bodies to promote equality of opportunity for disabled people by the Disability Discrimination Act 2005. Discrimination, within the terms of the 1995 Act, includes the failure to make 'reasonable adjustments' to enable a disabled person to use a service of the same quality and on the same terms as a non-disabled person. Since April 2006, public authorities in England and Wales have a duty to

* There is some anecdotal and some research evidence that some of the groups of parents covered by this knowledge review are more likely to have children with special educational needs and some will be disabled children.

proactively eliminate discriminatory practices, policies and procedures, eliminate barriers and ensure equal access to and participation in society of disabled people.⁵³ Public authorities in Northern Ireland already had this duty.

2.4 The policy framework for maternity services

The maternity services standard in the *National service framework for children, young people and maternity services* contains a clear recognition of the needs of disabled parents and parents-to-be.⁵⁴ This is partly couched in terms of recognising the responsibilities of maternity services to comply with the Disability Discrimination Act 1995. Thus, the section of the standard which covers birth requires that:

All NHS maternity care providers ensure that maternity units and services are:

- accessible to disabled women in line with the Disability Discrimination Act 1995 (including home births where appropriate)
- innovative and flexible in meeting the needs of women with communication and other disabilities
- informed by best practice from settings and regions across the country in caring for disabled women.⁵⁵

There is also recognition of the need for inter-agency working where women have additional support needs relating to long-term medical conditions (such as HIV/AIDS) or substance misuse.⁵⁶ The role of fathers is acknowledged throughout the document although there is no explicit recognition that some may be disabled or have additional support needs themselves.

2.5 The policy framework for adult social care

There is some acknowledgement in the adult social care policy framework that people with physical and/or sensory impairments, learning difficulties or mental health problems may also be parents. The White Paper *Improving the life chances of disabled people*⁵⁷ contains a number of references to disabled people's experiences as parents. It does not,

however, make any specific commitments to address their support needs. On the other hand, the proposed outcomes for adult social care, published by the Commission for Social Care Inspection, do include support for parenting roles.⁵⁸

While *Valuing people*, the national learning disability strategy for England, mentioned the need to support parents with learning difficulties, very little so far has been done to implement this.⁵⁹ Consultative documents for Wales (*Fulfilling the promises*) and Northern Ireland (*Equal lives*) fail to mention parenting roles. The Section 7 guidance on service principles and service responses, issued by the Welsh Assembly Government in 2004, reiterates the commitment that people with learning difficulties should have 'the right to live an ordinary life in the community' but makes no reference to the role of being a parent.⁶⁰

The *National service framework for long-term conditions* does not recognise the assistance that parents may need to continue looking after their children when they develop a condition such as multiple sclerosis, or acquire a brain injury, for example. There is reference to the need to ensure that children do not take on 'inappropriate caring responsibilities'⁶¹ but no suggestions as to how this can be done, and the only references to the relationship between children's and adults' services is in the context of the transition to adulthood for children with long-term conditions.

While it is recognised within adult mental health policies that some users of adult mental health services may be parents, there has been a tendency to focus on child protection issues rather than on support for the parenting role. Thus, the *National service framework for mental health* states that 'Professionals in adult mental health services should be familiar with local child protection procedures and know how to obtain specific advice quickly'.⁶² There is, however, an acknowledgement that 'Where the person with mental illness is a parent, health and local authorities should not assume that the child or children can undertake the necessary caring responsibilities. The parent should be supported in their parenting role and services provided so that the [child] is able to benefit from the same life chances as all other children, and have the opportunity for a full education, and leisure and social activities'.⁶³ Most other references to parental mental health in the national service framework relate to preventative measures that can be taken, to for example, promote the mental health of isolated new mothers.

The *Women's mental health strategy* (for England) issued by the Department of Health in 2002, recognised that the majority of women who use mental health services have dependent children, but there were no specific proposals to address their needs as parents although a range of good practice examples given included support with parenting.⁶⁴ There is only one recognition that some people using mental health services will also be parents in the recent assessment of the implementation of the *National service framework for mental health*. This appears on page 68 and refers to the need to 'highlight areas of interface, such as the care of children affected by parental mental illness'.⁶⁵ However, the recent annual report of the National Social Inclusion Programme (which follows the Social Exclusion Unit's report *Mental health and social exclusion*) has a section on 'social networks' which is mainly about parenting. The report recognises that 'There can often be a gap between the service provision for adults with mental health problems and services provided for children', and proposes joint work with SCIE to produce national guidelines.⁶⁶

The Welsh updated *National service framework for mental health*, published in 2005, commits the Welsh Assembly Government and local authorities/local health boards to implement local and national action to promote social inclusion. Included within this is specific action to meet the needs of parents who have mental health problems.⁶⁷ In Northern Ireland, the recently published *Strategic framework for adult mental health services* only recognises parenting roles in a section on carers but does contain a recommendation that: 'Service users who are parents should be supported in their parenting role'.⁶⁸

The Department of Health's *Mental health and deafness – towards equity and access: Best practice guidance* sets out how the *National service framework for mental health* should be implemented for d/Deaf people in England.⁶⁹ However, in neither this document nor the consultation document which preceded it are the needs of d/Deaf parents identified. The identification of family support issues is entirely concerned with d/Deaf children.

There is more recognition that some users of services for people who misuse drugs will be parents. *Models of care for the treatment of drug misusers* is the national service framework for this area of policy and practice.⁷⁰ It includes a section on parents and pregnant women, and sets out the care pathways that should be covered where a parent or an

expectant parent is misusing drugs. The National Treatment Agency is currently developing a similar policy document to cover people who misuse alcohol. The government's response⁷¹ to *Hidden harm*,⁷² a report on the effects on children of problem drug misuse, also illustrated a recognition that policy must address the needs of parents and their children. For example, the government accepted the report's recommendation that there should be 'A coordinated range of resources capable of providing real support to families with drug problems, directed both at assisting parents and protecting and helping children'. In Northern Ireland, the recent consultation report issued by the Bamford Review of Mental Health and Learning Disability recognises the needs of parents and children in families affected by parental substance abuse.⁷³

The majority of parents with HIV/AIDS in the UK are black Africans and almost all of them live in England. The Department of Health, together with the African HIV Policy Network and the National Aids Trust, issued *HIV and Aids in African communities: A framework for better prevention and care* in 2005. This document is aimed at local health and social services commissioners and service providers within both the statutory and voluntary sectors, and identifies appropriate service responses for families affected by HIV/AIDS.⁷⁴

While there is some recognition within the adult social care policy framework that some of those who need support will be parents, and may well need support in their parenting role, the overall impression – apart from the policy framework for substance abuse – is that these support needs are included more or less as an afterthought. There is little sense of parenting roles being treated as a central issue in adult social care. Moreover, what recognition there is of parenting roles tends to be concerned with mothers. Men's parenting roles and responsibilities have been more or less invisible within the adult social care policy framework and little or no attention has been paid to meeting their additional support needs.

2.6 Legislative framework for adult social care

There is, however, recognition of parenting roles within legislation relating to adult social care. Adults who come within the definition of a disabled person within community care legislation, or who 'appear to be in need of community care services'⁷⁵ are entitled to an assessment of

their needs. Policy guidance on eligibility for services requires that family roles and responsibilities are taken into account in all four eligibility levels set out in the guidance. In determining eligibility, for example, ‘critical’ level includes ‘vital family and other social roles and responsibilities cannot or will not be undertaken’. ‘Substantial’ level includes ‘the majority of family and other social roles and responsibilities cannot or will not be undertaken’⁷⁶ and similar terminology is used in the Welsh equivalent document, *Health and social care for adults: Creating a unified and fair system for assessing and managing care – Guidance for local authorities and health services*.⁷⁷

Adults’ social services are also required to take into account the possible effects of not meeting levels of need which currently do not qualify (as ‘critical’ or ‘substantial’ for example): ‘The council should have satisfied itself that needs would not significantly worsen or increase in the foreseeable future for the lack of help, and thereby compromise key aspects of independence, including involvement in employment, training and education and parenting responsibilities’.⁷⁸

Those people who have been assessed as being eligible for support must be offered direct payments as an alternative to services, if this is what they prefer (and if they meet the qualifying criteria set out in the *Direct payments regulations*). Guidance on implementing direct payments states that ‘Councils should ensure that needs assessments for disabled adults include parenting responsibilities’.^{79, 80}

The extension of direct payments in lieu of services provided under section 17 of the Children Act 1989 (as amended by the Health and Social Care Act 2001, section 58) is an important mechanism for adults’ and children’s services to work together. As the direct payments guidance points out, a ‘holistic family assessment, taking account of the needs and views of children and parents’ is already required under section 7 guidance relating to children.^{81, 82} *Fair access to care services* practice guidance states that ‘It will be important for children and family teams to have agreed policies and protocols with adult teams’ on how to respond to the needs of families where the parent is disabled.⁸³ However, as discussed below there is no specific requirement within the children’s policy framework for children’s services to work with adults’ services.

One anomaly and potential injustice has been created by the wording of the trust deed for the Independent Living Fund. Although assistance with carrying out parenting tasks is covered by *Fair access to care services*,

such assistance is specifically excluded from the remit of the Independent Living Fund by its trust deed. This is an anomaly which, arguably, creates unequal opportunities for disabled parents with high level support needs and may contravene the Disability Equality Duty (implemented from April 2006).

2.7 The legislative framework relating to housing needs

A disabled person and their family may be entitled to temporary housing from the housing authority if they are homeless and in priority need.^{84,85} Housing authorities must also give 'reasonable preference' when allocating social housing to people who have health (including mental health) problems which are made worse by their current accommodation or whose mobility problems mean their home is unsuitable for them.

If a community care assessment, carried out by the social services authority, has established a housing need then the social services authority has a duty (under section 21 of the National Assistance Act 1948) to ensure that this need is met. Various judicial reviews have confirmed this duty, confirming also that the accommodation must be appropriate to meet the person's needs (see www.careandhealthlaw.com for details).

The legislative framework relating to housing adaptations provides important entitlements for people who require adaptations to be able to look after their children. The Housing (Grants, Construction and Regeneration) Act 1996 places a duty on local housing authorities to make a disabled facilities grant where the social services authority has assessed a disabled person as needing adaptations. Eligible need includes where a parent would not be able to care for their child safely without changes to their accommodation. The grant is subject to a means test but responsibility remains with the social services authority to ensure that assessed need for housing adaptations is met.⁸⁶ 'This includes those cases where the help needed goes beyond what is available through the disabled facilities grant, or where a grant is not available for any reason, or where a disabled person cannot raise their assessed contribution.'⁸⁷

2.8 Children's policy and legislative framework

Since 1997 children's policy has been dominated by two main issues: a recognition of the need for preventative and early intervention to support families; and secondly, concerns about protecting children from harm, with an increasing emphasis on the extent and effects of neglect, and the need for communication and coordination across different agencies and professions in contact with vulnerable children. Although the current policy framework, *Every child matters*, was prompted by the Victoria Climbié inquiry,⁸⁸ it is as concerned with prevention and early intervention as it is with child protection. Improving children's outcomes is now the clear driver for policy and practice.

Following the Green Paper *Supporting families*, published in 1998, there has been an expansion of family support services through the setting up of Sure Start, the Children's Fund and the Parenting Fund. In addition, the policy goal of reducing child poverty by 25 per cent by 2005 was followed by the introduction of the minimum wage and changes in the tax and benefits systems to increase the incomes of the poorest families. The current policy aim is to halve child poverty by 2010.⁸⁹ Such policies have been part of the Labour Government's recognition that children's welfare is integrally linked to their parents' experiences of social exclusion.

At the same time a specific policy emphasis on outcomes for children – first set out in the Quality Protects (in England) and Children First (Wales) programmes – has been continued into the *Every child matters* framework and there is now a statutory requirement on children's services authorities to improve 'well-being' for all children in their area. Well-being has five components:

- physical and mental health and emotional well-being
- protection from harm and neglect
- education, training and recreation
- the contribution made by children to society
- social and economic well-being.

Children's services authorities are required to take the lead in drawing up strategic children and young people's plans to identify where these outcomes need to be improved and how to bring about these

improvements. The child care Bill, when enacted, will in addition place a duty on local authorities to reduce inequalities in well-being between young children in their area.

Within the framework and policies aimed at supporting families, there is some recognition of the need to target particularly families where parents have additional support needs. The Parenting Fund made £16.4 million funding available for the voluntary sector to target services to families who have had less access to services, strengthen the voluntary sector's network of family support services and highlight and promote good practice. Disabled parents and those affected by substance abuse are included as priority groups. Thirty-four projects, out of a total of 134, say that they provide services for families affected by disability, although the majority of these concern services to families with disabled children rather than disabled parents (see www.parentingfund.org).

Sure Start brings together early education, child care, health and family support to 'deliver the best start in life for every child'. It funds local programmes and children's centres and there is a commitment to provide 3,500 children's centres in England by 2010. The planning guidance for children's centres recommends that consideration be given to ensuring access for parents whose take-up of services is traditionally low and this includes 'parents with a learning disability or mental health problem, those experiencing domestic violence or misusing drugs'.⁹⁰ Practice guidance on setting up and running children's centres states that additional support should be provided for families where parents have learning difficulties, mental health problems or drug and/or alcohol problems.⁹¹ However, an opportunity has been missed to include sections on how to support these groups of parents within the guidance.

The Children Act 1989 places a general duty on local authorities (now children's services authorities):

- - to safeguard and promote the welfare of children within their area who are in need
- - so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.⁹²

There is, therefore, a focus on supporting parents to look after their children (where appropriate for their children's welfare) at the heart of

the Children Act 1989. However, there is very patchy recognition within the children's policy and legislative framework of the need for children's services to work with adults' services where parents have support needs relating to impairment, illness or substance abuse problems. For example, there is very little recognition within Section 7 guidance in *The framework for the assessment of children in need and their families*,^{93,94} of the need for children's services to work with adult social care services. The core standards of the *National service framework for children, young people and maternity services* are an exception in that there is a section on 'parents with specific needs', which states that agencies should 'have in place effective formal and informal collaborative arrangements between services for adults, children and young people, and families'.⁹⁵ However, the national service framework is unusual in its recognition of the role of adults' services.

The Children Act 2004 (which applies to England and Wales but not Northern Ireland as yet) and accompanying guidance are strangely silent on the role of adults' social services. The Children Act 2004 requires that children's services authorities work together with their 'relevant partners', to promote the well-being of all children in their locality. Specific action is likely to be required to enable disabled parents and those with other additional support needs to play their full part in achieving the five outcomes for their children, and disabled parents' entitlements under community care legislation are particularly relevant. However, guidance has a limited amount to say about this. For example, section 10 of the Children Act 2004 requires children's services authorities to work with their 'relevant partners' but adult social care is not mentioned as a 'relevant partner', although the statutory guidance on the role of director of children's services does mention the need to work with adults' services.⁹⁶ Adults' services are required to be represented on local safeguarding children boards but the statutory duties referred to in the *Working together to safeguard children* guidance do not include those of adults' social services. Thus, there is no reference anywhere in the guidance to the entitlements to support that disabled parents have, or of good practice examples of supporting families where parents have additional needs. Guidance on *The children and young people's plan*⁹⁷ has a similarly limited view of the role of adults' services when it states: 'Planning for services for children and young people will require some coordination with services for adults, for example to enable young people, particularly those with learning

difficulties and disabilities, to move smoothly to services for adults, and in respect of young carers who cannot be supported through services for children and young people alone'.⁹⁷

Very few of the materials being produced by the Department for Education and Skills in the context of the implementation of *Every child matters: Change for children* refer to adults' social services. For example, the A–Z list of agencies on the website on multi-agency working does not include adult social care, learning disability or mental health services (see www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/workingwithothers/agencyatoz/). Drug action teams are listed but no information is provided about their role of working with parents with drug and/or alcohol problems (the inference being that their relevance relates to their work with young people). This reflects the general impression within the *Every child matters* framework that 'multi-agency working' does not include adults' social care services.

The role of adults' services in supporting parents to look after their children is also missing from the documentation relating to annual performance assessments and joint area reviews. However, the Commission for Social Care Inspection recently carried out a special study of the extent to which (where children are placed on the child protection register) parents' needs are identified and adults' services are involved. It is intended that the resulting report should inform local authorities' annual performance assessments.⁹⁸

2.9 Conclusion

Within both the children's and adults' social care framework, there has been a recognition of the need for inter-agency coordination at both strategic and front-line level. Within the adult social care policy framework this has been a key issue from the *NHS plan* in 2000, through to the 2005 Green Paper *Independence, well-being and choice*,⁹⁹ and the White Paper *Our health, our care, our say*.¹⁰⁰ However, the focus has been almost entirely on relationships between health and social care for adults, and it could be argued that the concern expressed by previous generations of policy-makers and commentators about the relationship between children's and adults' services has fallen off the agenda.

The setting up of social services departments in 1968, following the *Seebohm report*, was dominated by the aim of integrating social services

across children's and adults' services so that duplication could be avoided and a more holistic approach taken to meeting families' needs. The current policy framework, *Every child matters*, is concerned with integration across children's services in education, health and social care, and arguably there is insufficient acknowledgement of the importance of adults' and children's services working together to address families' needs.

A final point to be made is that the obligations placed on public authorities by the Human Rights Act 1998 underpin all the aforementioned legislation and policy and, in particular, Article 8 – the right to respect for private and family life – and Article 12 – the right to marry and found a family.

In the next chapter, we look at what research tells us about the perspectives of parents and children.

Families' perspectives, barriers and needs

It is important to state at the outset that most of the research literature relevant to this knowledge review concerns parents who, for one reason or another, are in touch with children's social services and/or specialist adults' services. We cannot say with confidence therefore that the findings from this research literature are valid for these groups of parents in general. Moreover, most of the research concerns their experiences of services, rather than their experiences as parents and what support they need to look after their children.

We cannot say that the findings relating to experiences and support needs apply equally to mothers and fathers. The literature often fails to differentiate but appears to be concerned with the experiences of mothers. Thus the specific support needs of fathers generally remain invisible.

This chapter summarises what we know from research about parents' and children's experiences, while Chapter 4 focuses on what the research tells us from the perspective of services and practitioners.

From the research literature it would appear that each of these groups of parents is at disproportionate risk of experiencing barriers to parenting, in addition to any difficulties created by their particular support needs. We start by summarising these general socio-economic barriers, before moving on to look at the specific support needs of these parents, and then discussing their experiences of services. A final section summarises what we know about the experiences of children.

Throughout this chapter we also refer to the views of parents who participated in the consultative groups to illustrate some of the research findings.

3.1 Socio-economic barriers

3.1.1 Poverty and unemployment

Disabled adults are twice as likely to live in low income households as their non-disabled counterparts, and their experiences of inequality have grown over the past 10 years.¹⁰¹

Long-standing disability or illness is correlated with unemployment. Young disabled people have similar educational and employment aspirations to their non-disabled counterparts but – by the age of 26 – are nearly four times as likely to be unemployed or economically inactive as non-disabled young people.¹⁰² Employment rates by impairment category are difficult to ascertain with accuracy, primarily because of problems with definitions, but those provided by the *Labour force survey* are commonly used. According to an analysis of the *Labour force survey* provided by the Disability Rights Commission, disabled people* with mental health problems have the lowest employment rates of all impairment categories, at only 20 per cent. For people with learning difficulties, the employment rate is 25 per cent. On the other hand, 62 per cent of people with hearing impairments are in employment.¹⁰³

Disabled people in employment are more likely to work in manual and lower-skilled occupations, and less likely to work in managerial, professional and high-skilled occupations. At £9.88 per hour, the average gross hourly pay of disabled employees is about 10 per cent less than that of non-disabled employees.¹⁰⁴ Moreover, disabled people in employment experience lower growth in earnings over their working careers and are more likely to exit paid employment.¹⁰⁵

The Department for Work and Pensions' analysis of *Labour force survey* statistics show that 'Couples with children where neither are disabled have a household employment rate of over 97 per cent. This drops to 78 per cent when at least one of the couple is disabled. Similarly, for non-disabled lone parents the employment rate of almost 60 per cent is significantly higher than for disabled lone parents at almost 40 per cent'.¹⁰⁶

* Note that the figures in this and the next paragraph relate to disabled people not disabled parents.

Low income is compounded by the additional costs that some parents incur because of their particular support needs. A detailed examination of the additional costs incurred by disabled people in general found that the weekly income of disabled people who are solely dependent on benefits is about £200 below the amount required for them to ensure an 'acceptable, equitable quality of life'.¹⁰⁷ This study did not include the additional costs incurred relating to parenting. The Disability Alliance, RADAR and Disabled Parents Network gathered anecdotal evidence of these types of costs, illustrating that the current benefits system does not recognise the 'extra costs incurred by disabled parents, which are different from – and often greater than – those incurred by disabled people who do not have children, and by non-disabled parents'.¹⁰⁸

These additional costs include buying safety equipment to assist in looking after children, adapting equipment, paying others to help with child care, buying ready-made meals, and the increased costs of leisure activities and holidays. Disabled parents can also incur additional transport costs: for example, one blind mother, who had been using public transport with confidence all her life – including after her first child was born – found this too difficult once her second child was born. 'Unable to hold her daughter's hand, and sort out a buggy and a baby, she was forced to travel everywhere by taxi.'¹⁰⁹

'Transport is a big problem. I'm often too tired to use public transport so can't take my kids out. Positively Women used to organise transport to their meetings which meant I could go, but it was cut.'

Parent with HIV.

'My DLA [Disability Living Allowance] goes on take-aways when I'm too tired to cook.'

Parent with long-term illness.

3.1.2 Poor housing

Overcrowding, poor physical housing conditions, and/or housing which is physically unsuitable are correlated with low income and can have particular consequences for the parents covered by this knowledge review. A survey of disabled parents' information needs found that housing was a key area of both difficulty and lack of information.¹¹⁰

'Emotionally my girls have been damaged by us being homeless and having to keep moving.'

Parent with long-term illness.

People with mental health problems are more likely than the general population to live in insecure rented housing and/or housing in a poor state of repair and twice as likely to be dissatisfied with their accommodation. They are four times more likely to say that their health has been made worse by their housing.¹¹¹

'Having been in temporary accommodation for years, the flat they then offered me had no heating or hot water when we moved in. There was pigeon infestation and flies, faeces in the back garden by the kitchen door, crack cocaine outside the front door, the keys for the window locks were missing, the intercom doesn't work so I don't know whether anyone's at the door, the back door doesn't shut properly. My son has to sleep with me in my bedroom because his room is uninhabitable.'

Parent with long-term medical condition and mental health problems.

Immigration status, discrimination and low income all combine to mean that parents with HIV/AIDS and their children are at risk of living in poor housing conditions and this can have a detrimental effect on their health.¹¹² Research concerning parents with a range of progressive medical conditions highlighted the barriers to accessing suitable housing. These include not being able to get a mortgage following diagnosis, and social housing allocation policies failing to take account of housing needs which arise as the condition progresses.¹¹³ A comparative study of parents with and without learning difficulties who had received core assessments by children's social services found that those with learning difficulties were more likely to experience housing problems.¹¹⁴

For parents with mobility impairments, the lack of choice associated with low income is compounded by the nature of the housing stock and problems with the disabled facilities grant system. 'There is a grave shortage of housing stock suitable for re-housing as an alternative to adaptation for disabled households in any tenure. For families, a wait of three years or more would be likely in 70 per cent of all authorities.'¹¹⁵

For a mother or father with a mobility impairment, the provision

of a stair lift, accessible toilet/bathroom and/or alterations to a kitchen can have a significant impact on both the ability of the parent to look after their children, and on the well-being (including the safety) of the children. Delays and difficulties in providing such adaptations can create significant risks to both parents and children. The underlying cause of much of this delay is the shortage of available resources: disabled facilities grants are a mandatory grant funded by a cash-limited budget and the consequence is that rationing takes the form of delays in processing applications.¹¹⁶

'I'm waiting for a stair lift. I can't get upstairs now and Natalie [10 years old] has to give herself a bath and get herself to bed and get herself up in the mornings – except when my ex-husband comes round and he can't do this when he's working early shifts. She's already fallen and bruised herself really badly.'

Parent with mobility impairment.

3.1.3 Poor neighbourhoods

Families living in the poorest neighbourhoods are more likely to be experiencing poor physical and mental health, and long-term illness and disability. Stress caused by environmental hazards, crime and anti-social behaviour is highlighted in one of the few studies which looked at parenting in difficult circumstances among parents in general, rather than those in touch with services.¹¹⁷ Poverty and material deprivation is compounded by the effects of, for example, not being able to let children play outside because of lack of local play space, dangers from traffic and dog fouling on the streets.

3.1.4 Negative attitudes and discrimination

'This time last year when my daughter was four months old, I carried her strapped to my front in a sling. I went out and about with great regularity, displaying new baby and new motherhood and wheeling proudly, and while there would be some clucking, mostly what I received were slightly odd looks. On one particular day we were at the newsagents, a shop I had been using for at least a couple of years.

At the till, the woman who had worked there throughout, blurted out: "Oh god, it's a baby! I thought it was a teddy bear."¹¹⁸

Some women experience negative attitudes to their pregnancy and parenthood: women with learning difficulties, physical or sensory impairments or mental health problems have all reported negative responses among professionals, family members and society generally. Parents with learning difficulties report harassment and bullying against them because of their learning difficulty and this can become a more common experience once they become parents. Their children can also be affected.^{119,120}

There is some evidence that negative responses to particular support needs or characteristics can result in lower standards of pre-natal and maternity care. The most recent report of confidential enquiries into maternal deaths states that 'There were instances where, in the compiling of the reports for this Enquiry, unwitting staff prejudices were revealed that may have had an effect on the care they provided'.¹²¹

Not everyone's difference is visible and, for example, fear of the reaction of universal services can mean that parents with mental health problems are reluctant to reveal their diagnosis.¹²² The stigma associated with HIV/AIDS can mean that parents are reluctant to seek, or say why, they need support. Anderson and Doyal's study of black African women with HIV living in London found that 'Stigma, both actual and perceived, had a profound impact on women's lives, making control of information about their situation a matter of acute concern. This had an effect on how women accessed health services and voluntary sector agencies'.¹²³

'People think you are to blame for having HIV. It's because you're African, or they think you're a prostitute or you use drugs.'

Parent with HIV

Negative attitudes – and anticipation of negative attitudes – about particular needs and circumstances can act as a barrier to parents seeking support from social care services. A number of research studies find that parents with mental health problems, drug and/or alcohol problems, or learning difficulties are reluctant to approach social services for fear that their children will be taken into care.^{124,125} Children living with parental alcohol abuse told Childline that they are reluctant to share

problems with adults who could help because of fear that they will be taken away from their families.¹²⁶ The secrecy and stigma associated with both alcohol and drug misuse can mean that parents are not getting the support they need and some children are living in situations where they may be at risk but they are not known to social services.¹²⁷

Parents in receipt of services via the Care Programme Approach and their children said they feared and experienced 'discriminatory responses from local and professional communities and agencies that may lead to family separations or child protection procedures.'¹²⁸ The researchers concluded that these fears can adversely affect parents' mental health and well-being over time.

Tarleton et al's study of parents with learning difficulties reported that 'The parents' anxiety and fear often resulted in them taking a deliberate stance against services and workers that they felt were threatening their family. This was particularly the case when they had had children removed in the past. This seemingly adversarial position and disengagement from children and family services could subsequently feed into children and family services' concerns about their parenting ability'.¹²⁹

'When social services are knocking on your door you become very proud and you can cut off your nose to spite your face.'

Parent with physical impairment.

3.1.5 Lack of information

Socio-economic deprivation is associated with a lack of information about both statutory and voluntary sector support services. A survey of parents in poor neighbourhoods found very little awareness of semi-formal support services for children or parents, with the exception of play groups. Awareness and take-up of services such as parenting education, lone parents support services, etc, was low, with 20 per cent never having used a support service and nearly two thirds having had no contact with services in the last three years.¹³⁰ This confirms previous research on the general lack of information among poor families about semi-formal support services available in their localities. While the survey found that support services were more likely to have been used by parents with current family and relationship problems, parents with the highest number of stress factors were no more likely than others to

access services. In addition, families on the lowest incomes, and minority ethnic parents were significantly less likely to have used support services in recent years.

While the families in the survey were more likely to be aware of, and use, formal services (such as health visitors, ante-natal classes, etc), 'Nevertheless, both awareness and take-up figures suggested that parents in poor environments are not being reached by so-called "universal services" intended for all, such as the health visiting service, let alone more "targeted services", such as social services'.¹³¹

Parents may lack information because it is not provided in a way that meets their particular requirements. This is a common experience among parents with learning difficulties and was a key issue raised at the 2005 National Gathering of Parents with Learning Difficulties.¹³² It is also an issue commonly raised by Deaf parents,¹³³ parents with visual impairments and deaf and blind parents. There may also be a failure generally to provide information for parents about formal services. For example, none of the protocols for partnership working with families affected by alcohol misuse and mental health problems which were examined by SCIE had produced information aimed at families.¹³⁴

A survey of disabled parents' access to information highlighted the particular difficulty that parents have in accessing information when family needs change suddenly.¹³⁵ Disabled people generally lack information about entitlements to support through the community care system. The government's recent review of the disabled facilities grant system found that 'information to service users and potential service users is mostly extremely poor, for fear of discovering need that cannot be met'.¹³⁶ Social services professionals themselves are often ill informed about the disabled facilities grant system and this can result, for example, in disabled parents not being 'told that there is specific mandatory disabled facilities grant provision to enable a disabled person to care for others in the household'.¹³⁷

Lack of information about what someone is entitled to can have a significant impact on both parents and children. For example, there is evidence that 'a considerable number of HIV-positive mothers continue to breastfeed their infants because they cannot afford infant formula milk'.¹³⁸ Yet, government guidance recommends that, where the cost of formula milk is the only reason why an HIV-infected woman feels unable

to avoid breastfeeding, clinics and doctors should consider prescribing formula milk.¹³⁹

Social isolation – created by poverty, discrimination and/or inaccessible communication methods – can mean that parents miss out on informal sources of information. For example, Deaf and deaf and blind parents have great difficulty picking up information through informal sources, such as at the school gate, or from the television or radio.*

3.2 The support needs of parents

This section summarises what we know about the particular support needs of these groups of parents – in other words, needs that are associated with physical and/or sensory impairment, learning difficulty, mental health problems, long-term illness or substance abuse. As already noted, however, there is a paucity of information about support needs from the point of view of parents, and most of the research findings concern their relationships with services.

A research project carried out by E. Lewis included interviews and group discussion with 35 parents and 30 children and young people living with HIV/AIDS. These were the findings.¹⁴⁰

Main messages

Parents need support with looking after their children when they are ill:

- -Support services need to recognise the intermittent nature of HIV-related illnesses.
- -'There is a crucial need for family support to take young people to school and pick them up when parents are too sick to take them.'

* This statement is based on anecdotal evidence given in two presentations: one by Suffolk Sensory Service at an Association of Directors of Social Services workshop in October 2005; the other by a worker from the Royal Association for the Deaf at a conference in Essex, November 2005.

- -Child care is needed during hospital appointments and during periods of hospitalisation and ill health.

Lack of appropriate help when it is needed means that children and young people have to take on inappropriate caring roles:

- -Domiciliary help has been 'inconsistent, infrequent and insufficient. The lack of such support has severe implications for young people taking on inappropriate caring roles'.

Parents and young people wanted consistent, flexible services:

- - 'Establishing long-term relationships and not having multiple support workers is important to building up confidence and trust in services.'
- - 'Young people and adults find having multiple service practitioners in their lives time-consuming and confusing', and 'can result in them focusing too much on HIV'.

Parents wanted information and support with telling their children about HIV:

- -Social stigma and negative connotations can mean parents are reluctant to tell their children about their ill health.
- -Disclosure is 'a process of ongoing information-giving' and many parents have begun the journey of telling their children, despite saying their children 'don't know'. 'Parents need to be reassured that it is possible to explain gradually about HIV before giving it frightening labels.'

3.2.1 Support needs in pregnancy and childbirth

There is very little research – other than from a medical perspective – concerning the experiences of pregnancy and childbirth for these groups of parents. The grey literature* provides a mixed picture, with some mothers reporting maternity services going out of their way to make appropriate adjustments while others experienced unequal access to services and negative attitudes from health care professionals. Liz Crow reports two dramatically different responses to her needs as a wheelchair user in two maternity units within the same geographical area – the one very positive and accessible, the other providing an environment which would have completely disabled her during labour and afterwards.¹⁴¹ Jackie Topp, who carried out narrative research for a PhD thesis on disabled women's experiences of pregnancy (see www.dppi.org.uk/journal/48/research.html) wrote:

‘How each woman's needs were recognised and addressed once in hospital varied considerably. The maternity environment was generally found to be suitable at both hospitals in the county and the attitudes of midwives were found to be generally helpful. Three participants highlighted how some staff went out of their way to ensure that their individual impairment needs were met but this seemed to happen as a result of a crisis rather than as planned support. It appeared that a woman's emotional needs in relation to her having an impairment, as well as the physical and emotional needs of becoming a mother, were often neither explored nor recognised during the pregnancy.’

Unequal access to maternity and other health services can have significant consequences for mothers and their babies. For example, babies born to mothers who are HIV-positive are much more likely to be infected themselves if their mother's status is undiagnosed or diagnosed later in pregnancy. Black and minority ethnic people with HIV are ‘consistently diagnosed later in the course of their infection than their white counterparts’.¹⁴² This is reflected in the numbers of people diagnosed

* ‘Grey literature’ is a term used to refer to sources such as internal reports, government documents, conference proceedings, theses, newsletters and so on.

with AIDS within three months of their diagnosis of HIV and in the fact that 'while numbers of AIDS diagnoses remain steady overall, they are rising for BME [black and minority ethnic] populations'.¹⁴³

3.2.2 Support to look after new-born babies

Some parents need support to look after their children right from the birth of a baby. While it is important not to make the assumption that all parents who fall into one of these groups will have difficulties bonding with their babies, this is certainly a risk for many parents if their specific support needs are not met.

Mothers who experience post-natal depression are now less likely to be offered a place in a specialist mother and baby unit as there has been a reduction in such units.¹⁴⁴ If a mother has to be admitted to psychiatric hospital she may therefore be separated from her child.

'A mother and baby unit would have helped my daughter.'
Grandparent looking after children of daughter who is mentally ill.

Jo Tunnard's review of research on parental drug misuse¹⁴⁵ highlighted the difficulties created when babies are born with opiate withdrawal symptoms and may need intensive care. In the past, mothers have been advised against breast feeding in this situation although in some maternity centres breast feeding is now encouraged not just for the mother/baby relationship but also as part of the opiate withdrawal process for the baby. Considerable efforts are made in special care baby units to enable mothers and fathers of premature babies to bond with them: this practice has not always been applied where the mother or father misuses drugs.

The physical environment within the home and/or lack of suitable equipment can cause practical difficulties for new parents with physical impairments.¹⁴⁶ Organisations such as Disability Pregnancy and Parenting International provide important information about equipment and different ways of caring for a new baby (see the journal *Disability, Pregnancy and Parenting International*). Where a mother or father needs assistance from someone else in the early days of a baby's life – either because of physical or sensory impairment or learning difficulty – it must be provided sensitively to avoid it affecting the bonding process.

3.2.3 Assistance to carry out the everyday tasks of parenting

Parents may need assistance to carry out the everyday tasks of parenting. The ongoing physical assistance that parents with physical impairments or long-term illness require is documented mainly through anecdotal evidence in the pages of journals such as *Disability, Pregnancy and Parenting International*, and small qualitative studies which mainly focus on specific impairments and the role played by professions such as occupational therapists.¹⁴⁷ Parents with learning difficulties will often require support to learn how to respond to and look after their child, and – like parents who require physical assistance – this support may need to be ongoing: ‘The most effective support is that which helps parents to learn and achieve by themselves’.¹⁴⁸

As children grow older, the assistance parents need may change. There is very little research on these experiences but, within the grey literature, parents with physical and/or sensory impairments, those with mental health support needs and parents with HIV/AIDS have all reported that they face particular barriers in getting their children to school. This need may fluctuate, according to the parent’s state of mental or physical health, or it may be an ongoing need for as long as the child is too young to take themselves to school. Parents have also reported difficulties in their relationships with schools, created by two main barriers: unhelpful or negative attitudes, and a failure to make buildings and communication accessible.¹⁴⁹

‘It would help if my children’s school knew and therefore understood the consequences of the illness. For example, there are times when it’s difficult to get the kids to school – when I have hospital appointments, when I’m too ill. It’s also difficult helping them with homework, and filling in the homework book which they expect you to do every day. I would love to tell the school – there’s some mornings when I’m so tired and my child will then be late for school. It would be good if I knew the teachers wouldn’t pick him out and tell him off for being late.’

Parent with HIV/AIDS.

Lack of support for parents with learning difficulties leads to increased stress and can reduce parenting capacity¹⁵⁰ and this is likely to be the case for other groups of parents. One father in a consultative group stressed that the support given should strengthen disabled people in carrying out their role as parents independently. For example, he wanted to have the opportunity to take his children to the park to play football without having to rely on his non-disabled partner being there.

A need for support among Deaf parents of hearing teenagers was raised in a series of workshops for Deaf parents run by the Deaf Studies Trust.¹⁵¹ However, there is very little research about the experience of parenting teenagers when a parent has one of the support needs which are the subject of this knowledge review. Sometimes, of course, parents with additional support needs experience the same kinds of problems with parenting that other parents do: parents with drug and/or alcohol problems told us that they found television programmes such as *Supernanny* useful for helping them with parenting; a parent with HIV said that, as a single mother, bringing up two sons was difficult and she felt they needed a 'male mentor and someone who understands the family background'.

3.2.4 Fluctuations in the need for assistance with parenting

Many of these parents experience fluctuations in their need for assistance with parenting. As Jo Tunnard remarks in her review of the research literature relating to parental mental health, 'It is important to bear in mind that a person's mental health state is not a fixed condition. Problems usually fluctuate over time, in response to a variety of stresses and other factors, and they may disappear and re-appear and be short term or enduring. This is so for those with a diagnosis of a severe condition as well as for those with a more moderate mental health problem'.¹⁵²

Fluctuations in support needs are also a feature of the lives of parents with HIV/AIDS and other long-term illnesses, and parents with substance abuse problems.

3.2.5 Parents who experience more than one risk factor

Parents may have a range of support needs. A survey of parents living in poor neighbourhoods found that 'The greater the number of stress factors

that were reported by parents, the less likely they were to be “coping” with parenting’.¹⁵³ The factors which showed the highest correlation with ‘not coping’ were: having a ‘difficult’ child, having a number of physical and emotional problems, ill health, being a lone parent and having more than two children.¹⁵⁴

Research generally finds that most parents in contact with children’s social services experience a range of problems,¹⁵⁵ and this is no different for the parents covered by this knowledge review. For example, many parents with learning difficulties who are in contact with social services experience one or more of the following additional stress factors: childhood abuse and/or neglect; growing up in care; domestic violence; alcohol abuse.¹⁵⁶ Analysis by Cheshire County Council of their children in need census data found a correlation between domestic violence and parental mental health problems among children in need.¹⁵⁷ This reflects a number of research studies, summarised by Tunnard,¹⁵⁸ which find that domestic violence is closely associated with mental health problems.

Many parents in contact with children’s social services also have children who are disabled and/or have special educational needs. This would also seem (from anecdotal evidence) to be true for the groups of parents covered by this knowledge review who are in contact with social services.

One key message from much of the research on both alcohol and drug misuse is that other factors can have as significant an impact on the ability of parents to promote their children’s well-being as substance abuse (see also the discussion below about children’s experiences). Indeed, a parent’s substance misuse may not be the most important factor affecting a child’s life, as Jo Tunnard cautions from her extensive review of research on parents with alcohol problems:

Although problem drinking can have a pervasive influence across family life, it is not the only feature of life, and it may not be the most worrying. The death of a close relative, family illness or some other traumatic event may be more upsetting for children.¹⁵⁹

3.2.6 Parents who experience a range of support needs

Parents with additional support needs may experience a range of difficulties, many of which have nothing to do with impairment, illness or

addiction but which are correlated with and exacerbate these conditions. They may have pressing needs for information, advice and advocacy in respect of housing, benefits and debt. Some will need support relating to immigration status, their children's schooling, finding a GP and other health services, and so on. For example, an evaluation of the Family Welfare Association's WellFamily Service found that 'Most users had more than one type of problem and the Family Support Coordinators provided a variety of kinds of support, including counselling, liaison with statutory agencies, advice and advocacy'.¹⁶⁰

The Coram Family's HIV project employed a family placement worker whose professional competence and background was in finding substitute care for children. However, she found she had to 'give advice and support' and 'act in an advocacy role regarding benefit claims, housing, immigration. The assessment cannot move forward until these have been dealt with'.¹⁶¹ She commented, 'Initially, it felt like breaking professional boundaries ...'.¹⁶² Such situations illustrate that the needs of parents with HIV/AIDS (like those of other parents covered by this knowledge review) do not fall neatly into professional boundaries.

3.2.7 Positive aspects of parental support needs

There are some circumstances where parental support needs have a positive impact on their children. Most research focuses on the negative impacts for parents and children when support needs are not adequately met. We do not know enough about positive experiences, with the partial exception of Deaf parents and Deaf children. Deaf children born to Deaf parents (about 5–10 per cent of deaf children) do better academically, are more socially mature and have more positive self-esteem than Deaf children born to hearing parents.¹⁶³ This is presumably related to the fact that Deaf parents of Deaf children are better able than hearing parents to communicate with their deaf child and to pass on the positive benefits of Deaf culture.

3.2.8 Parents' awareness of children's difficulties associated with parental support needs

Parents are often aware of the difficulties their children may experience because of parental needs and circumstances. Qualitative studies illus-

trate parents' awareness of the impact of drug misuse on their families, for example. Parents have spoken of:

- - the way in which their pursuit of drugs can take precedence over their children's everyday needs
- - the fluctuating emotional states and capacities that are a feature of problem drug use
- - the shortage of money and problems associated with this – lack of food, heating, problems with paying the rent and risk of eviction
- - their attempts to hide their drug use from their children and, at the same time, their recognition that their children usually know
- - the fact that going to school is an opportunity for their children to get away from the situation at home, and how much they value the opportunities their children would have if they did well at school.¹⁶⁴

'Children sometimes see and hear things that children should not have to see or hear. It can help for them to have someone to talk this through with.'

Parent with drug and/or alcohol problems.

Parents in the consultative groups appreciated help with activities for their children – either with or without their parents – such as after-school clubs, Saturday groups and outings. These things helped to make up for the difficulties that parents had in arranging such activities for their children – because of lack of money and/or lack of energy or ability.

'I just want to stay in all the time because I'm so tired but my children, they want to go out all the time. It's very difficult.'

Parent with HIV.

3.2.9 The role of the extended family and informal community networks

Extended family and informal community networks may be particularly important for these groups of parents and their children. The role of the extended family is particularly important for parents with learning difficulties.¹⁶⁵ A recent survey of people with learning difficulties in England found that, among those whose children were living with them, almost

60 per cent of the parents were living either with their own parents or with other relatives.¹⁶⁶ This would seem to confirm anecdotal evidence that parents with learning difficulties are more likely to be able to keep their children if they have support from extended family.

Research on the experiences of families where there is parental drug misuse suggests that the existence of support from extended family members is crucial to children's well-being and also for their parents. Grandparents play an important role in both supporting parents to seek and maintain treatment, and looking after grandchildren.¹⁶⁷ We do not have any research evidence of the experiences of minority ethnic disabled parents, but where a family's religion and/or culture stresses the role of the extended family, we might also expect this to be an important part of the experiences of disabled parents and those with additional support needs.^{168, 169} It is important, however, not to make any assumptions about the nature of these experiences for different minority ethnic groups as we do not have sufficient research evidence on these issues.

Chapter 4 identifies friends and family placements as a policy and practice issue. As at March 2004, there were 7,800 'looked after' children who had been formally placed with friends or family.¹⁷⁰ There is anecdotal evidence that 'friends and family care is being used as a placement to an increasing extent where there is serious parental drug and alcohol misuse, and grandparents are often the relatives who agree to take on the care of the child/ren'.¹⁷¹ In addition, there are 'an unknown number of arrangements which are made privately between family and friends'.¹⁷²

While 'kinship care' is associated with greater stability for children and better continuity in terms of family and cultural issues than foster care, there is also evidence that kinship carers are likely to experience greater economic difficulties and poorer accommodation than non-kin foster carers.¹⁷³ The grandparents consultative group that took part in the research for this knowledge review highlighted that some grandparents are not only incurring costs of looking after their grandchildren but are also providing continuing financial support to their adult children. Some of the difficulties that grandparents experience with services are discussed below in Section 3 of this chapter.

3.2.10 Parents' needs in the context of child protection procedures and care proceedings

Parents often need advocacy support and adjustments to standard procedures when social services act on concerns about children's welfare. Disabled parents often require adjustments to standard child protection procedures and care proceedings if their particular access needs are to be met – and indeed this is an entitlement under disability discrimination legislation (see Chapter 2). Such adjustments may include additional time to meet access needs, the provision of information in suitable formats, and advocacy support.

Tarleton et al's recent work on parents with learning difficulties¹⁷⁴ echoes previous studies which identified the need for independent advocacy when families become subject to child protection procedures and care proceedings.^{175, 176} This is also an issue which arises in the grey literature concerning most of these groups of parents.

Sometimes, the policy and legislative framework can itself create barriers to equal treatment and so necessitate a need for adjustments and support. For example, Alison Richards, who had* significant experience of the family courts system and of the support needs of parents and extended family members, expressed her concern that the aims and targets associated with the new adoption legislation can make it harder to meet disabled parents' access needs, including their needs for advocacy support.¹⁷⁷ This was also a concern raised by parents with learning difficulties at a national gathering in 2005.¹⁷⁸

3.3 Parents' experiences of services

There is very little rigorous evaluation of the effects of service interventions. Research does, however, give a fairly clear indication both of what parents value about support services and what difficulties they encounter with support services.

* Alison, who worked as legal advisor for the Family Rights Group and who did very valuable work which was appreciated by many people, died in September 2005.

A national gathering of over 200 parents with learning difficulties and those supporting them said these are the things that help people with learning difficulties to be good parents:

- - accessible information about the parent's and baby's health and about how to look after a baby
- - self-advocacy groups (coming together with other parents)
- - getting support before things go wrong and become a crisis
- - being assessed in their own home, not in an unfamiliar residential family centre
- - assessment and support by people who understand about learning difficulties
- - advocacy
- - making courts more accessible
- - support for fathers
- - support for women and men experiencing violent relationships.¹⁷⁹

3.3.1 The type of support that parents value

Parents in general value support that is easy to access, is not stigmatising, and that creates and enhances informal support networks.¹⁸⁰ A summary of government-funded research on parents' experiences of formal support services concluded that 'what parents wanted from formal services was consistent across all the studies that asked the question'.¹⁸¹ In general terms they wanted:

- - practical and professional help
- - their views to be taken seriously and to be treated as partners
- - services to be supportive, respectful and considerate.

Parents also said they 'wanted to feel in control in dealing with parenting problems' and 'first wanted information to help them solve problems and then specialist advice'.¹⁸²

In terms of what we know about disabled parents' experiences, the (mainly qualitative) research literature indicates that disabled parents and parents with additional support needs value flexible, practical support. This includes support that meets the personal assistance needs associated with physical impairment, practical support with getting

children to and from school, assistance with getting children into a routine, and so on. Direct payments have been particularly useful as a way of enabling parents to have more choice and control over the way support is provided.^{183, 184} So too have voluntary sector services which provide support tailored to each family's circumstances.¹⁸⁵ These services have proved particularly helpful for parents with mental health problems and those with drug and/or alcohol problems.

Services which meet a range of support needs are much appreciated by parents.¹⁸⁶ These include information, advice and advocacy, and counselling.^{187, 188} Parents particularly appreciate services which enable them to gain support from other parents in similar situations.¹⁸⁹ This range of services is more often found within the voluntary sector than the statutory sector. The consultative groups of parents with HIV and those with drug and/or alcohol problems spoke of how much they valued the opportunity to come together to share experiences.

The PEACE outreach project¹⁹⁰ in Bromley provided a service to 13 mothers over a six-month period. The most common primary diagnosis was schizophrenia and two thirds of the mothers identified themselves as black or minority ethnic. The project used an assertive outreach model, focusing on individual and immediate needs, offering one-to-one support and facilitating group meetings and outings.

All 13 women reported increased skills and confidence as a result of using the project; and most had either taken up education, training or voluntary opportunities or returned to paid employment. All had reported their social networks as poor or fragmented at the start of their involvement, but now all but one reported their networks as either stable or strong. All had identified their mental health as either poor or not coping at the start of the project but now only one defined herself as not coping. In the two years before being referred to the project, the 13 women had had a total of 10 hospital admissions; after engaging with the project, only one woman had been admitted to hospital. Women also reported fewer visits to their GP.

Some parents value services that enable them to have a break from caring for their children.^{191, 192} Although the message from parents is that they want 'ordinary' experiences for their children¹⁹³ and do not want them to be stigmatised through their contact with services,¹⁹⁴ sometimes the particular needs of parents mean that they appreciate services that have specialist expertise. Parents with HIV who we consulted for this knowledge review mentioned two particular services which they valued. One was in a health setting where parents and their children could stay for a few days. Parents had a rest and were looked after while their children were involved in activities and taken on outings. The other was a voluntary organisation working with parents and children with HIV, which provides workers to take children on outings, both individually and in groups. Such services are particularly likely to be valued by parents who are ill, are in pain and/or who experience high levels of stress, and by those who have few informal sources of support to draw on.

Universal health care and voluntary sector services are often preferred by parents as they do not have the stigma attached to statutory social services.^{195, 196}

Parents value services which, in meeting their access needs, enable them to support their children's education.¹⁹⁷

Bristol Education and Lifelong Learning has a British Sign Language (BSL) interpreting fund to help the authority meet the cost of BSL interpreting for Deaf parents. A contract has been agreed with South West Communications Services Unit (CSU) to provide BSL interpreters for parents who attend meetings about their children's education.

Support services which address needs relating to both impairment and disabling barriers are valued by parents.

Suffolk Sensory Service*, funded by the Supporting People programme, provides a service to adults who are Deaf, visually impaired or who are deaf and blind. This often means working within a situation where the adult is a parent. Some of the 20 staff are deaf themselves, which means that they not only have the ability to communicate with Deaf parents but also share a common culture. An example was given of a Deaf mother who hadn't picked up what her responsibilities were as a parent because of her isolation from all the usual sources of information about being a parent. The support worker, herself a Deaf mother, was able to help the mother and her children to establish routines and safe practices. The service also provides a language aide service, where workers go to people's homes or into educational settings and teach BSL. This can involve helping children learn to sign so they can communicate with their parents.

Parent education programmes, tailored to address specific needs, are welcomed by some parents. Deaf Parenting UK, for example, has run deaf parenting skills courses, using trainers who are Deaf BSL users themselves (www.deafparent.org.uk). Sure Start Carlisle has also run groups for Deaf parents, and has helped them to form their own self-help group (www.childrensncscasestudies.dh.gov.uk).

3.3.2 Difficulties with statutory services

Parents report a number of problems in their contact with statutory services. The specific issues relating to policy and practice are discussed in Chapter 4. Here we focus on the difficulties that parents have reported in terms of their contact with health and social services.

* Information presented here is from a presentation by Suffolk Sensory Service at a workshop on supporting disabled parents held by the Eastern Region of the Association of Directors of Social Services on 31 October 2005.

- - Failures of communication between different services and professionals can have a significant impact on parents if it means that their particular needs are not recognised. This includes failures of communication when a woman becomes pregnant. The most recent report on confidential enquiries into maternal deaths states that some women, who had pre-existing serious medical or psychiatric problems, experienced a lack of communication between obstetric services and other services responsible for their care.¹⁹⁸ One example of an attempt to prevent problems arising is the *Maternity care guidelines for women with special needs*, adopted by Milton Keynes maternity services and which covers women with spinal lesions, multiple sclerosis, sensory impairments, and learning difficulties.
- - Disabled parents have reported disputes between children's and adults' social services about who is responsible for funding the support they need with carrying out parenting tasks.^{199, 200}

'I got bounced between the adults' social worker and the children's social worker.'

Parent with HIV.

- - Parents with learning difficulties, in particular, find that they can be in contact with large numbers of professionals, and this is confusing and disempowering.^{201, 202}
- - Many of the parents in the groups covered by this review do not meet the eligibility thresholds for adults' social services. Most parents with learning difficulties, for example, who come to the attention of children's social services are 'not known to adult learning disability services, and because the thresholds of these services were so high these parents were unlikely to receive support from them'.²⁰³
- - At the same time, most of these parents are unlikely to meet eligibility thresholds for support from children's social services until they get into difficulties – often because of a lack of support. For example, most parents with HIV/AIDS do not exhibit the level or type of need which commonly triggers intervention from children and family social services. Their need usually relates to their illness, and possibly to their immigration status and their separation from their extended family.²⁰⁴ It is also common that only short-term crisis interventions are available from children's social services once significant difficulties

are experienced.²⁰⁵ A group of parents with drug problems identified a common dilemma: they were reluctant to approach social services for help because of concerns that child protection would be identified as an issue, yet, on the other hand, they reported that unless their children were identified as at risk they would not get any support from social services or existing support would be withdrawn.²⁰⁶

- - Parents with learning difficulties often get access to independent advocacy services only once a crisis has been reached – usually when court proceedings have already started – and there is little or no support once a child is temporarily removed.^{207, 208} It has been argued that this lack of support makes it very unlikely that parents can prove to children's social services or to the courts that they are 'good enough' as parents.²⁰⁹ Parents in our consultative groups told us how much they valued local organisations which provided advice and advocacy.

'The service Julian [advocacy worker] provides is brilliant. He helps you write letters, comes with you to meetings so you don't feel vulnerable. He lifts your spirits so you feel more comfortable with social services.'

Parent of African-Caribbean origin, with long-term medical condition.

- - Parents sometimes receive confusing and contradictory messages from children's social services about what constitutes 'good enough' parenting.²¹⁰
- - People often do not fall neatly into just one 'service user group' and the failure to address co-existing support needs can create difficulties for parents.²¹¹ A comparison between women who were clinically depressed and women who were both clinically depressed and dependent on alcohol found that the latter group had significantly higher levels of difficulty in parenting.²¹² A multi-centre study of substance misuse and mental health problems found that many people who were described as having a dual diagnosis received no specialist intervention.²¹³ The policy and practice issues relating to 'dual diagnosis' are discussed in Chapter 4.
- - One study found a high level of unmet social, personal and sometimes medical needs among black disabled or ill parents.²¹⁴ The consultative

group of black and minority ethnic disabled parents told us that social care services do not always address their particular support needs.

‘Social services don’t always take account of extra time needed to cook particular types of food. Or extra time to, for example, cane row my hair. It takes 20 minutes to grease up my skin. Social services take the attitude that you’re always asking for more but if we didn’t have to ask them we wouldn’t ask them.’

Mother of African-Caribbean origin, with a physical impairment.

Where extended family members are providing substitute care – on a short- or long-term basis – their support needs are not always acknowledged by children’s social services.²¹⁵ Not all families in this situation will want the children concerned to become formally ‘looked after’, yet the lack of this legal status has often meant a lack of support from children’s social services – although a judicial review established that it is unlawful for local authorities to treat ‘friends and family’ carers differently from ‘stranger carers’ in terms of payment and support (*L (A child) v Manchester City Council*, 2002). Lack of recognition of their role and lack of support was a key issue raised by the grandparents’ consultative group, and echoes the issues raised by research.^{216, 217}

There is little research concerning the experiences of grandparents who are helping their adult children to parent. Particular difficulties can be experienced when adult mental health services have responsibilities relating to patient confidentiality and this was an issue raised by our consultative group of grandparents.

‘I would have appreciated information and advice about how to support my daughter when she became ill.’

Grandparent looking after children of daughter who uses mental health services.

Some grandparents are providing significant support for their children to ensure the well-being of their grandchildren. However, this is not an issue that receives much attention in the research literature.

'Social services don't recognise grandparents' role as support for adult children.'

Grandparent supporting daughter with learning difficulties.

3.4 Children's experiences

Almost all the research about the children of disabled parents concerns children who are in contact with children's social services. It is unlikely, therefore, to be representative, as the majority of children of disabled parents are not in contact with children's services. In an attempt to get the perspective of the wider group of children, we consulted with a group of children and young people whose parents had a physical or sensory impairment but who had not been identified as 'young carers'. These children talked about:

- - what type of assistance was helpful to their family, that is, assistants who are friendly and enjoyable to be with, who join in family activities without interfering in family business, and who are reliable and flexible
- - parental involvement in children's lives, that is, parents should have the assistance they need to be able to take children to school, to a football match, shopping, and so on
- - the benefits of having a disabled parent, which included having contact with other families who have similar experiences
- - the disadvantages of having a disabled parent, which included having other people stare at your parents or get embarrassed about disability.

These are all issues which are raised in the research literature. What research there is seems to indicate that the children of these groups of parents have a number of experiences in common. A review of research on children's experiences of living with domestic violence, parental physical or mental health problems or substance abuse found, for example, that the most common feelings experienced across a whole range of situations were: 'love and loyalty, feeling frightened, worried, sad, angry, embarrassed and isolated'.²¹⁸ The review also found that children valued similar types of support: they wanted age-appropriate information about their parents' condition or support needs; opportunities to spend time

away from home and to have fun (but they needed to know that things were alright at home); and to get to know children experiencing the same problems.

3.4.1 Children's needs arising from the social stigma attached to their parents' needs

Children can be adversely affected by the social stigma attached to their parents' support needs and they often appreciate contact with other young people who have similar experiences. Adults who were brought up by parents with learning difficulties have reported being bullied and picked on at school and in their local community.²¹⁹ Children whose parents have additional support needs can acquire labels which are stigmatising and isolating.²²⁰

The concerns expressed by the group of children we consulted with for this review about the negative attitudes their families sometimes encounter reflects the parents' experiences documented in the grey literature. It is also evident that children, like parents, benefit from meeting with others who share similar circumstances. The many studies²²¹ that report how much children and young people appreciate young carers' projects reflect the benefits that young people experience from meeting and spending time with peers who have similar experiences.

Regardless of whether, or the extent to which, a young person takes on a caring role, it can be tough living in a family affected by parental mental health problems, substance abuse, HIV/AIDS, physical or sensory impairment, or learning difficulty – not least because of the social stigma which often accompanies such experiences. Sharing experiences with others who know what you're talking about is very helpful to children and young people and is often only possible once they are identified as 'young carers' and thereby become eligible for young carers' services. This is a benefit recognised by parents as well: an isolated single parent in the consultative group of black and minority ethnic parents said that when social services offered her children to attend a young carers' group: 'I allowed them to go 'cos I thought they would socialise', and she felt that they did benefit from the group.

However, concern has been expressed that the development of peer support and social opportunities for children of disabled parents should not be used as a substitute for the provision of services to enable disabled

adults to carry out their parenting role.^{222, 223} Moreover, not all young people supporting an ill or disabled parent identify with the term 'young carer'. In particular, a study of young black people reported that: 'This categorisation made no positive difference to the support they or their families received, and it made them feel different from other young people'.²²⁴

3.4.2 Factors associated with poor outcomes for children

It is clear from the research that a range of factors can create poor outcomes for children and it is very difficult to disentangle the effects of different factors. While impairment, illness or substance abuse are risk factors for children's welfare, arguably it is their co-existence with other factors that creates significant risk.^{225, 226} For example, while there is a considerable amount of research which shows a correlation between parental mental health problems and difficulties for children (extending into adulthood), very little of this research looks at the effects of other factors such as family conflict, lack of informal support, or parenting styles.²²⁷

There is more evidence about the impact of substance misuse on children than that of parental disability or illness but even here the research indicates a complex interaction of different factors.

One large-scale, longitudinal, New Zealand study found that by the age of 15, teenagers with at least one parent with alcohol problems were more likely to experience mental health, substance use and/or behavioural problems.²²⁸ Scandinavian control studies have found that the children of fathers with alcohol problems were more likely to experience difficulties at school, mental ill health and stress.²²⁹

On the other hand, other research tends to indicate that it is the combination of problem drinking with additional negative factors, such as family conflict, which threaten children's health and well-being, rather than problem drinking itself.²³⁰ The various research reviews^{231, 232, 233} report there is evidence that children growing up with parents who have alcohol problems are at risk of experiencing separation from one or both parents, inconsistent parenting behaviour, and poor school attendance and performance. Children of parents with alcohol problems report vulnerability to physical assault on themselves, as well as witnessing physical assault on other family members.²³⁴

The evidence about whether having a parent with alcohol problems has a long-term impact on children as they grow into adulthood is equivocal. One study examined the experiences of 250 young adults who had grown up with parents with alcohol problems alongside a comparison group whose parents had not had a drink problem. Although those whose parents had alcohol problems recalled very difficult childhoods and negative experiences, there were no significant differences between the two groups in terms of current self-esteem, life satisfaction, anxiety, depression and criminality. Where both parents were problem drinkers, outcomes were more likely to be negative but even here the more important factor seemed to be the presence of conflict and disruption during childhood rather than the problem drinking itself.²³⁵ Interestingly, the same research found that there were more positive relationships between siblings where parents had alcohol problems compared with children in the control group.

In terms of the experiences of children whose parents misuse drugs, the reviews of research carried out by the Advisory Council on Drugs,²³⁶ by Jo Tunnard,²³⁷ and by SCIE²³⁸ all conclude that these children can be negatively affected from conception onwards. A mother's use of drugs, poor nutrition and the risk of HIV and hepatitis infection can affect foetal development; babies and children can be exposed to risks within the home from both parental behaviour and an unsafe and unhealthy environment associated with drug taking; and the stigma, social isolation and criminal behaviour which often accompany problem drug taking all have a negative impact on children's life chances.

The small number of qualitative studies, summarised in the report of the Advisory Council on the Misuse of Drugs, illustrate the impact on children of their parents' drug problems:

- - Children described their parents as not 'being there' for them – emotionally, as well as sometimes being physically absent.
- - Children understood from an early age about the stigma associated with drugs, and the consequences of discovery, and felt burdened to keep their family circumstances secret.
- - Children were afraid for the well-being of their parents, and were sometimes so anxious they were reluctant to leave the parent by going to school or playing with friends.²³⁹

While children of drug-misusing parents may be at material and physical risk, it is the emotional impact that they find hardest to cope with:

Their focus was not risk, nor particularly their experiences of material deprivation, rather it tended to be the social and emotional effects of living with parents who too often put their drug-related needs first. Primarily, these children and young people described feelings of hurt, rejection, shame, sadness and anger over their parents' drug problems, and it was with difficulty that they lived with these feelings.²⁴⁰

Other sources, however, emphasise the importance of factors other than substance misuse for determining children's experiences. Tunnard's review of research concerning drug-misusing parents concludes that many such parents provide their children with '... warmth and stability. It is important to look at people's behaviour, not the label that may have been applied to them'.²⁴¹

It is experiences which are often associated with drug and/or alcohol misuse which cause long-lasting negative effects on children: 'The main issue which causes children to develop problems [is] not parental drinking but the family disruption and disharmony that often (usually) accompanies the substance misuse. Most research shows that what upsets children most is not parental drinking, or even parental drunkenness or intoxication, but the rows and arguments between their parents which disrupt family life'.²⁴² Physical abuse was identified as the main problem for four out of 10 children living with parental alcohol abuse who called Childline.²⁴³ The absence of a parent because of separation or divorce, or a prison sentence, are also factors which have a direct negative impact on children. So too does the poverty and poor housing which can accompany substance misuse.

The research literature concerning outcomes for children whose parents have additional support needs would seem to show that, in most cases (and with the possible exception of alcohol abuse), the risk to children arising from their parents' needs is not of physical or sexual abuse but rather a threat to their attachments and normal development. Where a range of factors combine to disrupt attachment and development, children may develop behavioural problems and experience mental health difficulties. Associated with this will often be problems with school attendance and with learning. Children may come to the attention of

services because of these problems but this is not always the case.²⁴⁴ While much of the literature argues that a holistic approach that addresses the needs of all family members is required, there is little evidence – from research on families' perspectives – that they are receiving this.

3.4.3 The impact on children of a lack of support for their parents

Lack of support from informal networks and inadequate formal support can mean children take on inappropriate roles within the family. This is more likely in lone parent families and those on low incomes. Research on children who have been identified as young carers finds that they 'can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere'.²⁴⁵

Most of the research concerning young carers is, like most of the research on disabled parents, small-scale and qualitative. There are fairly consistent messages, however, about families' experiences of formal services. Such services are said to be 'intrusive and of limited value', 'slow and rigid in their delivery'.²⁴⁶ A lack of communication and coordination between children's and adults' services was also a commonly reported problem.

Children in these studies also reported that professionals often have little understanding of their situation and do not pay enough attention to their knowledge or their concerns. Some children and their parents report that formal services expect children to provide practical assistance to their parents and this was certainly the experience of some of the parents in our consultative groups.

'Social services suggested that my children do things like help me out of bed and cook for me and they [the children] said no ... My children were eaten up inside.'

Parent of African/Caribbean origin with mobility impairment.

A consultation with young people affected by parental mental ill health, learning or physical difficulties in the London Borough of Greenwich heard that some young people felt that they were sometimes treated as carers, and sometimes professionals wouldn't speak to them about their parents' needs. As one 12-year-old said: 'I have a nasty feeling it's to do

with jobs other people don't want. I'm definitely a carer at weekends – no one talks about confidentiality then'.²⁴⁷

A study of the experiences of parents with HIV/AIDS and their children found that 'Domiciliary help was inconsistent, infrequent and insufficient. The lack of such support has severe implications for young people taking on inappropriate caring roles. They took pride and enjoyment in some of these helping roles, but other responsibilities were too arduous. Young people illustrated a lack of choice in taking on these roles'.²⁴⁸

Research concerning the experiences of children whose parents have mental health problems highlights that they may be more likely than other children to take on an emotional caring role and this can cause problems for them. Children can also be afraid of what is going on at home while they are not there and this can act as a disincentive to school attendance.²⁴⁹

3.4.4 The positive aspects of taking on a caring role

In some circumstances, taking on a caring role can increase children's sense of independence and maturity.²⁵⁰ A caring role may also help mitigate some of the other difficulties children are living with. For example, a study of families whose parents were in receipt of services through the Care Programme Approach found, through interviewing the children concerned, that a caring role can 'serve to offset some of the adverse consequences of symptomatic behaviours among parents that can lead to emotional "absences" particularly during difficult time in their illness'.²⁵¹ This was illustrated by one young person: 'I like to make (mum) laugh and that, and she'll start laughing, we'll have a laugh and a joke and that. She'll forget all about it, and then I know I've helped. Or when she's struggling, I know I can help her and then, it's just a sense of achievement'.²⁵²

Children's concerns and anxieties can also sometimes be alleviated by a caring role. The researchers conclude: 'In some instances caring can help to enhance parent–child relationships and can make children feel *included* when often, outside family environs, they are socially and politically *excluded* from health and social service practice'.²⁵³

In addition, there are circumstances where parents choose to rely on their children rather than on services and this can give children a signifi-

cant sense of importance and value. This is particularly the case for some asylum-seeking families where parents need assistance with interpreting. Even when interpreting services are available, parents and children in one study reported that they 'were fearful of translators and did not trust them entirely'.²⁵⁴ While it is often argued that parents should not rely on children to interpret for them, it is important to acknowledge that sometimes this is a role that children value (as well as sometimes being a role that they find upsetting or burdensome).

3.4.5 Protective factors which increase children's resilience

A review of evidence about what works in promoting children's resilience concludes that although 'resilience is most successfully promoted through multi-systemic interventions directed at the family, the community and the child', the most important intervention is building parenting capacity while children are young.²⁵⁵ Long-term relationships between children and important adults have generally been found to be the most important protective factor in research that measures outcomes for children.

Jo Tunnard, in her review of research on the experiences of families affected by parental alcohol problems, finds that the following factors are correlated with good outcomes for children:

- - a stable relationship with a non-drinking parent or other adult
- - nurturing from others within the family
- - active use of an informal network outside the family for advice and assistance
- - parents providing structure and control, including a united and caring front, family activities, and time and attention
- - positive influences at school
- - the maintenance of self-esteem and coping skills in the child, including an acquired sense of meaning and faith about life.²⁵⁶

3.5 Conclusion

The research literature on the experiences and needs of the parents and their children covered by this knowledge review is dominated by gaps in evidence. We do not know enough about parents who are not in contact with services, and even among those who are, most of the

evidence concerns their experiences of services rather than their wider needs and circumstances.

Chapter 4 looks at the policy and practice issues arising from the research and includes the experiences of practitioners.

Policy and practice issues

This chapter summarises the policy and practice issues that have emerged from the review of the research literature and includes findings relating to the experiences of professionals. We start by identifying the difficulties apparent in the way services respond to families' needs, before moving on to discuss evidence of progress.

4.1 Barriers experienced by services in responding to the needs of disabled parents and their children

4.1.1 Adults' services' responses to parenting roles and responsibilities

Given the failure to recognise parenting roles adequately within the policy framework – as identified in Chapter 2 – it is not surprising that these roles and responsibilities are often not addressed within adults' services. This failure is evident in adults' services in relation to each of the groups covered by this review. There is some evidence that this is changing but there are still barriers to responding to the family context in which individual needs are situated.

Some adult learning disability services, for example, report a lack of confidence and experience in addressing the needs of parents.²⁵⁷ Tarleton et al found a general increase in referrals to adult learning disability teams but just over half of those supporting parents with learning difficulties did not have specific training to cover child care issues.²⁵⁸ As highlighted in Chapter 3, eligibility criteria for adult learning disability services often mean that parents with learning difficulties do not receive this service.²⁵⁹ For example, a study of a community team for people with learning disabilities in an East London borough found that parents with IQ scores of 70–85 comprised a significant proportion of referrals but following assessment none were offered support or intervention in the medium to long term. At the same time, generic family support services were reported as inadequate to meet their needs.²⁶⁰

The invisibility of men's parenting roles and responsibilities within the policy and legislative framework – referred to in Chapter 2 – is reflected in the general failure of services to address fathers' support needs. 'Parents [with HIV/AIDS] say that services for men, and especially single fathers, are few and far between'.²⁶¹ Most of the research concerning how services respond to parents' support needs concerns mothers and there is very little in the research literature about fathers.

In spite of the policy framework provided by *Models of care*, many drug and alcohol treatment services still focus on individuals and not on the family context in which they are living.²⁶² Although there has been progress in recent years there still appears to be a lack of attention to families' needs. A qualitative study of alcohol treatment agencies in one part of England found that 'Respondents reported either a lack of formal policies and guidelines obliging and directing services to meet the needs of children and families affected by alcohol within their organisations, or they reported having little knowledge of these policies should they exist'.²⁶³

Adults' services – divided as they are into specialisms – can struggle to meet the needs of the many service users whose needs cross service boundaries. There is, for example, well-documented evidence of the links between mental health problems and substance misuse, yet a survey within one London mental health trust found that the majority of substance misuse service staff said they did not feel competent to carry out a mental health assessment, and a similar proportion of mental health service staff did not feel competent to carry out a substance misuse assessment.²⁶⁴

4.1.2 The cost implications of fragmented responses to needs

At neither local nor national level are there any mechanisms for taking account of the cost implications of not spending money on meeting disabled people's needs in one area on other service areas and budgets.²⁶⁵ This can mean that a failure to meet one set of needs results in, not just adverse consequences for the individuals concerned, but also unnecessary burdens on other budgets. One example of this concerns adaptations and equipment. The recent review of the disabled facilities grant summarised the findings of research on the effectiveness of adaptations:

They produce significant health gains and prevent accidents and admission to residential care. Research has shown major improvements in quality of life and independence for disabled facilities grant recipients. Disabled children and their siblings benefit in development, education and social contact. Carers suffer less stress and have reduced likelihood of back injury.²⁶⁶

The Audit Commission has calculated that one year's delay in providing an adaptation costs up to £4,000 in extra home care hours.²⁶⁷ There has not been a similar calculation done in relation to disabled parents but the costs of delaying, or not providing, adaptations may be even higher. Yet decisions are taken – both locally and nationally – about the provision of adaptations and equipment without any cognizance being taken of the consequences for health or social care expenditure.

A similar point can be made about the implications of local policies which use an IQ of 70 to determine eligibility for adult learning disability services. Most people with learning difficulties who become parents will not meet this eligibility criterion, but they may need support with parenting. Similarly, their children may not meet the relatively high eligibility criteria for children in need or child protection. Without such support, they and their children may eventually meet such thresholds – by which time a considerable amount of resources may be required either to enable the children to remain with their parents or to remove them into care. The same situation occurs when a parent with mental health problems does not meet the eligibility criteria for adult mental health services.

4.1.3 The influence of local factors

Practitioners are sometimes more influenced by local factors – such as shortage of resources, or custom and practice – than by the policy and legislative framework within which they are working.²⁶⁸ This is clear from both judicial reviews and investigations by the Local Government Ombudsmen (see, for example, summaries of decisions relating to social services at www.lgo.org.uk/report.htm). Although we have identified some ways in which the policy framework does not adequately recognise parenting roles among disabled people or those with additional support needs, the legislative framework is quite clear that they are entitled to

support with parenting tasks – as pointed out by Michael Preston-Shoot.²⁶⁹ Policy and practice guidance^{270, 271} also makes it clear that adults' social services should have scrutinised their existing policies and practices concerning eligibility to ensure that they meet the *Fair access to care services* guidance.

Moreover, the original policy guidance on the implementation of community care made it clear that assessments should be comprehensive.²⁷² This policy guidance also requires that assessments are needed, rather than service- or resource-led, and explore all aspects of needs before taking a decision about eligibility. Various judicial reviews have confirmed these important elements of assessments yet there continues to be evidence, within the grey literature, of failures to follow these statutory requirements.

There is substantial anecdotal evidence that some learning disability services use IQ levels as a cut-off point for restricting eligibility to assessments and/or responses to need. This is unlikely to be lawful, as local authorities have a general duty not to 'fetter their discretion' and to consider each individual's circumstances. As Michael Preston-Shoot points out, 'operating blanket policies in community care services would breach the duty to assess an individual's need for services.'^{273, 274} It would further fetter discretion by neglecting the possibility that this case may require departure from agreed eligibility criteria'.²⁷⁵ Local authorities must not operate blanket exclusions from the definition of 'disabled person' and thereby deny an individual an entitlement to assessment without – as they are required to do – taking 'full account of individual circumstances'.²⁷⁶ Exclusions of, for example, people with ME (Myalgic Encephalomyelitis/Encephalopathy, or chronic fatigue syndrome), or epilepsy, or above a certain level of IQ, from entitlements under the Disabled Persons Act 1986 or the Chronically Sick and Disabled Persons Act 1970 are unlawful.

4.1.4 Communication and coordination problems between different professionals and services

Family life is not aligned with agency boundaries. Research and policy debate has clearly identified the problems caused by service boundaries and the specialisation of services, problems which are not limited to

the British context.²⁷⁷ This not only creates difficulties for parents, as identified in Chapter 3, but also creates problems for practitioners.

A review of government-funded research on supporting families summarised a number of cross-cutting themes in the context of inter-agency working:

- - There were few good examples of effective inter-agency working or cooperation between agencies.
- - Cooperation often depended on energetic individuals rather than structures.
- - Services tended to protect their own boundaries and restrict their responses to their own areas of expertise.
- - Professional anxieties and funding issues often seemed to be part of this.²⁷⁸

In terms of responding to the needs of parents covered by this knowledge review, there are particular difficulties created by organisational and professional boundaries between both children's and adults' services, and between health, education and social care. There are also important issues relating to relationships between the statutory and voluntary sector, which are discussed later.

4.1.4.1 Children's and adults' services

All the reviews of research literature, referred to in the introduction, highlight that there are particular failures of coordination and cooperation between adults' and children's services. While there have been some improvements in recent years, which are reflected in our locality survey, the gulf between adults' and children's services is still apparent and (some have argued) is likely to increase as a result of the integration of education and children's social care and the organisational separation from adults' social services. A key message from the most recent inspections of children's social services was that 'in some places there is insufficient coordination between adults' and children's social services to ensure that parents receive practical support or that issues about their parenting capacity are addressed'.²⁷⁹ This echoes the earlier findings of the inspection of services to disabled parents²⁸⁰ and also of an analysis of serious case reviews.²⁸¹

There is, for example, considerable evidence of a lack of communication, cooperation and joint working across adults' and children's services where a parent has a learning disability. The problems arising from this lack of coordination are exacerbated where parents with learning difficulties have additional mental health, substance abuse and domestic violence problems, as *The Children Act report 2002* recognised.²⁸² In the grey literature, there is much anecdotal evidence of children and families social workers believing that adult learning disability services do not pay sufficient attention to children's welfare; and of adult learning disability services believing that children and families social workers have little understanding of the needs of parents with learning difficulties. A recent survey of services in contact with parents with learning difficulties found that adults' services often felt that children's services workers did not know how to communicate appropriately with these parents and this could result in unintended discrimination.²⁸³

As Jo Tunnard points out in her review of research relating to parents with mental health problems, those working in adults' and children's services 'inhabit different worlds of work and they find it difficult to communicate across their different agendas'.²⁸⁴ Children's services workers can feel that adult mental health workers are too focused on parents' needs and concerned about client confidentiality, while adult mental health workers may have little understanding of the pressures and statutory duties that lead children's services to institute care proceedings. Children and families teams have reported particular problems caused by high eligibility thresholds set by adult mental health teams.²⁸⁵ In a number of serious case reviews, lack of communication and joint working by adult mental health and children's services have been identified as a problem²⁸⁶ (for more recent cases, see *Executive summary of the 'W' children*, www.sheffield.gov.uk/safe—sound/protection-from-abuse/sscb/serious-case-reviews)

There are also problems of communication and coordination within specialist services. For example, a study of services in the West Midlands looked at links between adults' and children's mental health services and found that, although a high percentage of adult mental health workers in the community reported that they had parents on their caseload, there was generally no way of recording parental status. Children of service users were not routinely assessed or offered any intervention.²⁸⁷ This seems to be a missed opportunity as almost two thirds of the adult

mental health workers (all of whom were trained in behavioural family therapy) said they would have felt confident in working with children of service users. The same study found that over half of those working in child and adolescent mental health services said that a significant proportion of children (ranging from a quarter to all) with whom they were in contact had a parent with mental health problems. Most of the workers were in contact with the parents, reported feeling confident in dealing with parents' mental health problems, and had links with local services which could help parents.²⁸⁸ However, eligibility criteria and service boundaries created barriers to collaborative working with adult mental health services and made a more family-focused approach difficult.

4.1.4.2 Health, education and social care

In a number of situations and circumstances, health, education and/or social care professionals will need to communicate and work with each other to maximise their effectiveness in meeting adults' or children's needs. Organisational boundaries and professional cultures can create barriers, although recent developments in both adults' and children's services are intended to address such difficulties.

Professionals working in universal services can feel that they lack the relevant skills or experience to deal with specific support needs and that they and their service users would benefit from close working relationships with specialist services. This is not always available, however. For example, a survey of health visitors in one London area found that they lacked confidence in supporting parents with mental health problems and reported feelings that they were working in isolation, without support from other agencies, and had inadequate knowledge in their work.²⁸⁹

A survey of 500 health and social care professionals concerned with parental mental health and child protection found that the most significant communication problems were between childcare social workers and psychiatrists within adults' services.²⁹⁰ Communication between general practitioners and child care workers was also often described as poor, reflecting the gulf between social care and health care services and professionals which has also been a feature of previous research.²⁹¹

Similar difficulties in working across the health and social care divide have been found among those working with parents with learning dif-

difficulties. For example, an audit and evaluation of services in one locality confirmed that differences in attitudes and approaches of health and social services staff can make joint working difficult and inhibit effective practice.²⁹²

As already identified, confidentiality can be a barrier to information sharing and, while this can sometimes be overcome by good working relationships and parental consent, parents will not always want confidential health information to be shared with others. This is particularly the case for parents with HIV,²⁹³ but has also been reported as a factor when parents have mental health and/or substance abuse problems.

There has been less research on the role of education professionals in meeting disabled parents' needs (although this is an issue frequently raised by parents in the grey literature). One study found that, although primary school teachers were able to identify risks and protective factors in cases of a parental mental illness, they were hampered by a lack of mechanisms for raising concerns and an absence of a shared understanding of issues and actions required across services and agencies.²⁹⁴ Although a clearer framework has been put in place – following the Climbié Inquiry – requiring different agencies (including schools and local education authorities) to work together, these requirements focus on safeguarding children rather than supporting the parental role. The role of those working in schools and other education establishments when concerns do not reach child protection thresholds is less clear.

4.1.4.3 Difficulties in the relationships between parents and children's social services

A number of difficulties have been identified in the relationship between children and families' social services and these groups of parents.

Within children's social services generally, there would appear to be contradictory beliefs among professionals about what constitutes 'good enough parenting'. A review of practitioner assessments of 'good enough parenting' found that, although there is consensus at the abstract level, once 'attempts are made to operationalise the concept of good enough parenting, a large number of apparent contradictions tend to emerge'.²⁹⁵ Moreover, this review also argues that practitioners in fact focus on identifying 'bad parenting', which has the effect of shifting 'the skill

base of child care practitioners away from preventive interventions and towards the forensic investigation of harm'.²⁹⁶

As a result of this general tendency, practitioners can then find it difficult to take the holistic approach to assessment intended by the *Framework for the assessment of children in need and their families* and tend to focus almost exclusively on parenting incapacity. It has been argued that this is particularly the case when a parent has additional support needs relating to impairment, illness, learning disability and/or substance abuse.²⁹⁷

A case has also been made in some of the research literature that children's social services experience barriers to working in partnership with parents because of their statutory safeguarding responsibilities. For example, a survey of 500 health and social care professionals in contact with families with parents who have mental health problems concluded that the statutory responsibilities of child care social workers made it difficult for them to be supportive of parents or gain their trust. The workers themselves reported that they lacked the capacity to play such a role. Unsurprisingly, children's social workers saw themselves as advocates for children rather than for parents.²⁹⁸ McGaw and Newman, in their review of 'what works' for parents with learning difficulties state that there is substantial tension between protecting children and upholding the rights of parents.²⁹⁹ However, Tarleton et al³⁰⁰ suggest that this polarisation of interests may be artificial because adults' services are protecting children by supporting parents to parent effectively. Tunnard, in her review of research on parental mental health, concludes that 'Parents, children and professionals have many ideas in common about what might make a positive difference to the quality of life of families living with mental health problems'.³⁰¹

One key factor which can get in the way of practitioners working in partnership with parents is that, by the time the level of a child's needs hits the high eligibility thresholds operated by children and families' services, parents are really struggling (see Tunnard, 2004 for a discussion of this issue in the context of parental mental health). Focus group discussions with professionals on their experiences of working with families where there are parental mental health problems and child care concerns highlighted that workers are both concerned about risk and experience this emphasis on risk to be restrictive.³⁰²

'We try to avoid risk too often, rather than manage it. Adults' and children's services need to share the risk and avoid blaming each other.'

Child care social worker at the Eastern Region Association of Directors of Social Services workshop on supporting disabled parents, October 2005.

Children's social services often struggle to provide the kind of flexible, practical support valued by parents. For example, some parents welcome a break from looking after their children, or need substitute care when they go into hospital, but the type of support they require does not sit easily within the current statutory or administrative framework for providing substitute care. A survey of local authority children's services found that concern about taking resources away from 'mainstream' fostering, and the low priority given to preventative services could create barriers to responding to this type of need. There was also widespread confusion about whether looked-after children regulations would apply, and, at the same time, a recognition that the stigma attached to 'foster care' and 'looked-after children' status could act as a deterrent to using such a service.³⁰³ The first newsletter of the Choice Protects programme – a government programme to improve foster care – focused on 'support foster care' and sought information about good practice examples.

Most families in contact with children's social services have a range of support needs³⁰⁴ but there is also some evidence that social workers do not always recognise or address the range of difficulties that parents experience. For example, a significant proportion of parents with mental health problems experience domestic violence, yet this key factor is not always recognised or responded to.³⁰⁵ Practitioners working with families who have particular support needs report that they need access to specialist support and information, which is not always available. A study of the response to parental substance misuse in child care social work teams found that social workers needed access to specialist support,³⁰⁶ and Tunnard³⁰⁷ highlighted how important it is that children's services workers understand about mental health problems and the implications for how to support families.

Some researchers comment that the main focus of children and families social work is on mothers, with not enough attention being paid to the role, and support needs, of fathers. According to the Family

Rights Group, there is no published research that examines the role and involvement of fathers in the child protection process.³⁰⁸

It has been argued that children's services do not always take a supportive enough approach to the role of the extended family, a role which can be crucial to the relationship between a parent with additional support needs and their children. Chapter 3 referred to difficulties identified by extended family members who take on the care of children. From the point of view of children's services practitioners, there is evidence of confusion about their responsibilities when children are looked after by relatives and a reluctance properly to support carers in this situation on the grounds that this might 'open the floodgates'.³⁰⁹ A discussion paper on 'friends and family care' recognises that 'social services have tended to allocate resources based on the legal status rather than the needs of the child ...' arguing that, in contrast, eligibility for services should be 'based on the needs of the child, not on the type of placement being considered'.³¹⁰ There is growing pressure for clearer guidance and encouragement of good practice.^{311, 312} The 2003–04 round of Choice Protects grants invited applications from services to enable family and friends carers to take in and care for a child or to support existing placements.

4.1.4.4 Parents with learning difficulties and children's social services

There has been particular controversy about the intervention of children's social services in the lives of parents with learning difficulties and their children. The children of parents with learning difficulties are more likely to be the subject of care orders, and to be freed for adoption, than the children of parents without learning difficulties. A study on care orders found that one in four of the children involved had a parent with a learning disability,³¹³ while a study on child protection applications to family courts found that 16 per cent involved a mother and/or a father with learning difficulties and that they were almost twice as likely as other parents to have their child freed for adoption.³¹⁴ Some advocacy organisations, academics and professionals have argued that this disproportionate risk of losing their children is the result of discriminatory attitudes and a failure to provide appropriate support.

In contrast, Hedy Cleaver and Don Nicholson's research (commis-

sioned by the Department for Education and Skills but so far unpublished) concludes that, far from 'draconian' and 'unjustifiable' action being taken, social workers may be too slow to intervene to safeguard the welfare of children of parents with learning difficulties.³¹⁵

The research looked at the implementation of the assessment framework for parents with learning difficulties in comparison to parents who did not have learning difficulties and found the following statistically significant differences:

- - Referrals of parents with learning difficulties are more likely to result in an assessment and less likely to result in no further action. They are also more likely to be for child protection concerns. Of cases that progressed to an initial assessment, a 'considerably greater proportion' progressed to a core assessment.³¹⁶
- - Children were more likely to have 'severe developmental needs'.³¹⁷
- - Social workers were more likely to record parenting as not adequate in three or more of the six dimensions in the assessment framework and over half of parents were recorded as having severe parenting difficulties compared with 11 per cent in the comparison group.³¹⁸
- - Parents with learning difficulties were more likely to be classified as having difficulties in 'family history and functioning' and housing.³¹⁹
- - Children living with a learning disabled parent were more likely to be classified as 'multiple problem cases'.³²⁰
- - When core assessments were carried out concerning parents with learning difficulties, they were less likely to be provided with information about their rights. However, the views of parents with learning difficulties were more likely to be recorded.³²¹
- - Parents with learning difficulties were more likely to receive continuing input from social services: almost two thirds of cases remained open to children and family teams two years after the initial assessment; two thirds of parents received services in their own right.³²²
- - Children of parents with learning difficulties were more likely to have had their names placed on the child protection register during the two-year follow-up period, were more likely to be in care and remain in care, and were more likely to be the subject of care orders.³²³
- - Social workers were no more likely to record that a specialist assessment had been carried out to inform the core assessment in the

case of parents with learning difficulties than with non-disabled parents.³²⁴

The authors concluded their interim report: ‘Given the extent of the difficulties identified by either the initial or core assessment, the response of social services to cases in the study group could not be seen to be draconian. Indeed it could be argued that social services interventions may not be sufficiently robust to adequately address the needs of this group of children.’³²⁵

While such findings may be a defence against accusations of unwarranted intervention, they can also be interpreted as evidence of inadequate support to parents and their children. It is particularly worrying that, given that other research evidence shows that most child care social workers lack experience of how to assess and support parents with learning difficulties, social workers did not seem to be adequately following assessment framework advice concerning specialist assessments.

4.1.5 The implications of gaps in research evidence

The development of appropriate policy and practice is inhibited by the gaps in research evidence. We have already identified (see Chapter 1) that there are significant gaps and inconsistencies in the available statistics about the numbers of families who fall into the groups which are the subject of this knowledge review. However, even if such information was available, this would not tell us how many families are likely to require support to look after their children, as it is the co-existence of disability, illness or substance abuse with socio-economic disadvantage which largely determines levels and types of need. There is also a dearth of research on the views and experiences of parents themselves. This is recognised in the various literature reviews: for example, while ‘there is an extensive literature that draws on the experience and analysis of professionals engaged in policy, practice and research, there are relatively few studies that have a particular focus on the views’ of families affected by parental mental health problems.³²⁶

Policy and service development is particularly inhibited by the dearth of rigorous evaluations of service interventions. As Jo Tunnard concludes: ‘Few approaches [to parental mental health problems] in the UK have been evaluated robustly’³²⁷ – a statement that can be applied

to interventions aimed at these groups of parents generally. Indeed, when Moran and colleagues reviewed the effectiveness of parenting support (not just in Britain but also internationally), they were not able to include evaluations of services to disabled parents as 'we found no evaluation studies of sufficient scientific merit to include'.³²⁸

In the absence of such research, the main influence on practitioners tends to be anecdotal evidence and this can open the gate to some unhelpful stereotyping of people and situations. For example, the lack of research on the role of fathers where a mother has additional support needs means it is difficult to challenge some strong messages which come from anecdotal evidence. Such 'evidence' includes anecdotes about some women with learning difficulties being targeted by paedophiles, and also anecdotal evidence of disproportionate experience of domestic violence among mothers with learning difficulties in contact with children's social services. Such experiences, in the face of a lack of research about the role of fathers in families affected by learning difficulties, can create negative stereotypes of such fathers. There is one piece of research which challenges this: Tim and Wendy Booth carried out secondary analysis of three of their earlier studies to examine widespread assumptions that men are 'either exploitative or bring troubles of their own to relationships'. Although these types of situations were found among the data, 'supportive men were in the majority among the families surveyed'.³²⁹

However, without further research to examine the reality of men's roles in the lives of women with learning difficulties, negative stereotypes remain.

4.1.6 Dissemination of evaluations of service interventions

Where there have been evaluations of service interventions, the dissemination of the results has often been very poor. For example, there are methods of supporting parents with learning difficulties which have proved successful – but knowledge of these methods does not appear to be widespread, particularly among children and families' services. There is certainly not enough research, but there have been some evaluations of practice which indicate which methods of support are more likely to be effective. The following evaluations have been (positively) critically appraised by SCIE, the Centre for Evidence Base Practice, and Research in Practice.

A Canadian learning disability service has been providing a parent education programme since 1981. Self-directed learning was developed to teach basic child care, health, and safety skills to parents with learning difficulties. 'Controlled field studies with 33 parents found that 96 per cent of the self-trained skills rapidly reached the same level seen in competent parents and were maintained for as long as 3.5 years.' Most of the parents also received other support services. These were families facing considerable difficulties: child protection services were involved in 79 per cent of families and all were living below the poverty line.³³⁰

Parents with learning difficulties who received a group education programme, together with home-based intervention, experienced a statistically significant improvement in self-concept and awareness in comparison with a control group of parents with learning difficulties who received home-based intervention only.³³¹ A further analysis, of the same programmes, indicated that group work on its own was less effective than programmes which also included concurrent home-based interventions.³³²

Social support and stress are negatively correlated among mothers with learning difficulties, 'suggesting that the former may buffer the adverse effects of the latter'.³³³ This finding is important as it challenges the assumption that the presence of learning disability overrides any other factors.

McGaw and Newman's analysis of 'what works' for parents with learning difficulties concluded:

- - A range of interventions are needed from which service providers can 'pick and mix' to suit the needs of the families they serve.
- - Interventions should be designed in association with a diagnostic and functional assessment. The intensity of the programme and mode of intervention (whether group work, individual programme, combinations of both, or residential) will be determined by the findings of this assessment.
- - Where indicated, long-term support should be provided for those families who need it. Families respond well to services which provide consistency and permanence in terms of staff support and resources.

- - Long-term funding is required to enable service providers to build a range of effective interventions and to have the skilled staff in place to use them.
- - Resources should be used that match the level of understanding and preferred approach (for example, pictures, modelling, role playing) of each parent who is involved with the service.
- - Interventions should promote transfer (otherwise known as generalisation) from one skill to another, or from one setting to another.³³⁴

4.2 Progress in addressing the barriers identified

Parents for Life Partnership is a multi-agency project, involving adults' and children's services, voluntary sector and adult learning services in one area of Essex. A pilot project was independently evaluated. The service comprises:

- an assessment (using a tool adapted from the *Framework for the assessment of children in need and their families*) to identify the parents' support needs
- a parenting group run for a total of 20 weeks, including six cooking skills sessions and a parenting skills programme of 14 weeks
- activity mornings for parents and children during school holidays
- community support facilitators who go into the home to give support during the 20 weeks
- Circles of Support,* a group organised by a voluntary organisation for parents who need continuing support.³³⁵

There is good practice being developed – sometimes following the death of a child or media-created 'scandal' – but this is usually happening in isolation at a local level (and sometimes even within a locality with little reference to other local services).

* 'Circle of Support' is a group of people who meet on a regular basis to help each other accomplish their personal goals in life: see www.circlesnetwork.org.uk.

When the Social Services Inspectorate carried out a national inspection in the late 1990s of services for disabled adults in their parenting role, only one of the eight local authorities inspected had adopted policies aimed at meeting the needs of disabled parents.³³⁶ The Joseph Rowntree Foundation's Task Force on Supporting Disabled Adults in their Parenting Role commissioned a survey of all English local authorities in 2000. One in four were able to provide policies and/or protocols, although most were in draft or in the early stages of use, while almost another one in four were undertaking work or had plans to do so.³³⁷ A survey of local authorities in Wales and Northern Ireland carried out for this knowledge review had a poor response rate (44 per cent) in spite of telephone follow-up. Of those responding, 12 out of 16 had no policies/protocols covering any of these groups of parents; four had policies/protocols concerning parents with physical and/or sensory impairment; four covered parents with substance misuse problems; three covered parents with mental health support needs; and one covered parents with learning difficulties.

Our locality survey (Part 2 of this knowledge review) looks in some detail at emerging good practice in five localities in England and Wales. Here we summarise some key themes in current developments.

4.2.1 Initiatives aimed at prevention and early intervention

The needs of disabled parents have started to be recognised in early interventions and preventative services initiatives. We identified in Chapter 2 that there has been some recognition of the needs of disabled parents within the Sure Start initiative and the Parenting Fund. Mind, in Croydon, has received funding from the Parenting Fund to develop its previous work with parents who have mental health support needs, and to start an outreach service. Three projects currently funded by Sure Start illustrate the potential for development of services:

- - Circles Network has been funded to develop a toolkit and deliver a training and mentorship programme facilitated by disabled parents for use by service providers. This will aim to improve the relationship between professionals and disabled parents.

- - Mencap has been funded to provide parenting and relationship support to people with learning difficulties who are in long-term relationships and wish to start a family.
- - Deafax are educating young Deaf people in parenting skills and relationship development.

CHANGE, a national learning disability organisation, was funded by the Department for Education and Skills to produce:

- - *Planning a baby*, an accessible book on how to get pregnant
- - *You and your baby*, an accessible book on looking after your new baby from birth to one.

It is currently working on:

- - *You and your small child*, a series of accessible books on looking after your children aged one–four
- - *Pregnancy and birth*, an accessible book about pregnancy and birth
- - a training pack for use by parents with learning difficulties to train health and social services professionals so they can better support parents with learning difficulties.

The Department for Education and Skills has also funded the Children's Society to work in partnership with the Disabled Parents Network to:

- - promote systems and preventative practice that will ensure that children do not have to undertake inappropriate levels of care for their parent(s)
- - advocate and support the development of whole family models of assessment and practice across all relevant agencies, and promote joined-up, interagency and interdepartmental working.

A final example concerns a project run by the National Children's Bureau, focusing on building children's resilience in families under stress, and involving 14 different statutory and voluntary sector agencies working with parents with mental health and/or substance abuse problems.

4.2.2 Working within a social model of disability to address disabling barriers

Some professionals and services are working within a social model of disability to identify and address the disabling barriers experienced by parents. This enables them, for example, to identify the barriers of negative attitudes and unequal access which may have a bigger impact on a parent's capacity than their impairment or condition in itself.

One area child protection committee has produced a manual for those involved in assessing parents with learning difficulties, which includes advice such as the following:

We can collect 'hard' facts, for example, the child's attendance at school and the frequency with which the parents attend parent/teacher interviews, but we also need to collect 'softer' information, such as what are the problems in getting the child to and from school? It may be that a child is consistently late because their mother wishes to avoid meeting other parents in the playground who she feels 'look down on me'. We may need to negotiate a change in time or situation of teacher/parent interviews or arrange for a friend or advocate to attend as well.³³⁸

In the voluntary sector, some services have been developed which address specific access needs. For example, Disability Pregnancy and Parenting International (DPPI) has received funding from the National Lottery to provide accessible information for d/Deaf parents and parents-to-be, by:

- - producing an educational DVD for Deaf parents about pregnancy and birth, due to launch early 2006. The DVD will be fully signed and subtitled and will feature Deaf families
- - producing a number of plain English information sheets for Deaf parents

- - supporting the development of the Deaf Parenting UK website to enable it to become a centre of information for Deaf parents (www.dppei.org.uk/deafparenting.html).

DPPI is also producing information in accessible formats for parents with visual impairments, starting with information about planning a baby, pregnancy, birth and early baby care. The second part of the project will produce information relating to school issues, as blind and partially-sighted parents have identified key barriers to their involvement with their children's education.

4.2.3 Assessment tools for working with people with learning difficulties

In the absence of national good practice guidance and a concern that existing assessment tools are not adequate for work with parents with learning difficulties, a few adults' and children's services are developing their own tools. The Special Parenting Service in Cornwall uses a parent assessment manual developed by Promoting Effective Parenting (www.pep-uk.org/prof/prof4.html). Training on using this manual has been provided to 935 professionals across the UK since 1997 and the effectiveness of the training is currently being evaluated.³³⁹ It is the assessment tool most frequently used by practitioners responding to Tarleton et al's survey of services to parents with learning difficulties.³⁴⁰ Norfolk's Area Child Protection Committee has published an assessment manual aimed at both children's and adults' workers³⁴¹ (see also the assessment tools listed in McGaw and Newman³⁴²).

4.2.4 Increasing recognition among specialist substance abuse services of the needs of parents with drug and/or alcohol problems

There is evidence of service development in supporting parents who have drug and/or alcohol problems. This has been accompanied by changes in the focus of treatment – from an almost exclusive focus on the individual towards wider recognition of the role that families play in supporting individuals and their role in recovery.³⁴³

The number of services in England and Wales offering support to

children and families affected by alcohol misuse doubled between 1997 and 2004 – although there are still only 59 and not all of them offer specialist expertise in working with children and families.^{344, 345} Adfam recently published guidance and quality standards for support services for the families of people who misuse drugs and/or alcohol.³⁴⁶

In addition, there has been more focus on the need for drug and alcohol treatment services both to help parents to increase their parenting capacity and to work with children's services to safeguard children's welfare. Alcohol Concern is running a parenting and alcohol project which aims to:

- - strengthen the capacity of alcohol treatment services to support clients who are parents to develop their parenting skills
- - develop the capacity of parenting professionals to work with parents who have alcohol-related problems.³⁴⁷

Alcohol Concern is also developing guidance for different professional groups who come into contact with children affected by family members with alcohol problems; and the Alcohol, Drugs and Family Research Programme at the University of Bath is developing a toolkit for working with children and families of problem alcohol and drug users.

SCIE's review of research on interventions to support substance-misusing parents and their children suggests that the following are helpful:

- - parent education programmes
- - support for substance-misusing fathers
- - residential programmes for parents and children.³⁴⁸

4.2.5 Development of protocols for partnership working

Put simply, a protocol is a standardised way of handling a particular situation. The *National service framework for children, young people and maternity services* provides a more specific definition: 'A protocol is a description of the steps taken to deliver care or treatment to a patient. It is designed to implement national standards, or to determine care provision by using the best available evidence if national standards are not available'.³⁴⁹

Faced with the kind of difficulties identified earlier in this chapter, a number of adults' and children's services have developed joint or multi-agency protocols for meeting the needs of disabled parents. Sometimes these encompass a range of support needs, some address one specific group of parents, while others focus on a particular stage of parenthood.

An example of the latter is Huntingdon's multi-agency pre-birth protocol. Partners to the protocol include: midwifery services, children's services, drug and/or alcohol services, mental health, learning disability and adults' social services, housing services, Connexions and teenage pregnancy services. The partner agencies have signed up to the aims of the protocol which are to:

- - provide universal support to pregnant women and their families
- - have a shared understanding of what contributes to making young babies vulnerable
- - promote a consistent approach to assessment in the ante-natal and early post-natal stages (common assessment approach)
- - ensure clear and regular information sharing takes place between all services
- - provide a process by which all services working with families in the statutory, voluntary and independent sectors can consider the welfare of the child irrespective of whether they are primarily working with adults
- - ensure that services are able to flexibly provide advice, information and work collaboratively to meet the identified needs
- - ensure that that a key worker will be identified who will coordinate services with the family.³⁵⁰

The protocol has an implementation strategy, which includes auditing the effect of its implementation.

SCIE's work on partnership working for parents with mental health and drug and/or alcohol problems concluded that 'a universal protocol [that is, one that covers all parents] is preferable, with supplementary and specific material about working with drug, alcohol and mental health problems'.³⁵¹ Camden's *Joint service protocol for children and families affected by mental illness* has been adopted by a number of other agencies. It separates out level of need/urgency of response required into four

categories: urgent/acute concerns; significant parenting/mental health concerns; parenting/mental health concerns; and coping, self-supported families. Joint assessments and working are required at the first two levels of concern; and either children and families' services or mental health services assess and provide support at the third level of concern.³⁵²

Inter-agency protocols require training programmes in order to implement them, in particular to increase understanding of each agency/service area's perspective, skills and framework. It can be a daunting task to train a multi-agency group with diverse experiences and knowledge base³⁵³ but such training is required to meet both parents' and children's needs.

Agencies report that the process of developing protocols is in itself useful as it requires collaboration in order to produce them.³⁵⁴ However, the gains made from this joint planning working can be lost if there is not a dissemination and implementation strategy to follow, and/or the protocol and any accompanying materials are not kept up to date.³⁵⁵ Some agencies have created a dedicated post to increase awareness of the protocol, facilitate its implementation and identify obstacles (as discussed in our locality survey). In other situations, however, protocols have been formally adopted but in practice remain unimplemented.³⁵⁶

Factors which help to encourage awareness and effective use of protocols include:

- - well-designed documents with a high quality of production and printing, which are easy to understand (using flow charts etc), easy to navigate and look authoritative
- - clarity of purpose. It is important that protocols set out clearly the different legal frameworks and assessment processes for the various agencies involved. Clearly listing the contents and separating instructions from supporting material makes the documents easier to use in practice environments.
- - credibility. Acknowledging areas of professional anxiety and the realities of practice increases a document's credibility among practitioners. Anticipating and articulating problems, and then offering solutions helps to make protocols both authoritative and useful.³⁵⁷

Local initiatives to promote better communication and coordination of responses to parenting needs have often involved local groups of disabled

people, and have sometimes been prompted by pressure from them. However, there would seem to be very little involvement of parents with mental health problems and/or drug and/or alcohol problems in the development of protocols and policies for partnership working.

SCIE has identified the importance of user involvement in:

- - helping to define the needs, outcomes and tasks for protocol content
- - receiving accessible versions of the protocol detailing what to expect – both as an entitlement to information but also as a lever for accountability, action and compliance
- - participating in monitoring and evaluation.³⁵⁸

There is little evidence of this type of involvement for people with mental health needs and/or drug and/or alcohol problems.

4.2.6 The role of the voluntary sector

Those working in statutory services value being able to refer parents to voluntary sector services, which provide flexible and practical support. An evaluation of the Family Welfare Association's WellFamily service – a 'single door' advice, information and support service in GP practices and health centres – found that 'GPs and other primary care professionals thought the Family Support Coordinators filled an important gap in helping patients with complex and/or psycho-social problems, so their own skills were used more effectively'.³⁵⁹ GPs also said that the early intervention by the WellFamily service prevented more serious problems developing and thus avoided referral to statutory social services.

Evaluation of the Family Welfare Association's Building Bridges projects (which support parents with mental health problems) has found that a range of health and social care professionals feel that the service eases the pressure on statutory services.³⁶⁰ In one area, health visitors found that there was a significant reduction in the number of 'vulnerable families' on their caseload because of the service provided by the Family Welfare Association.

The voluntary sector also provides important advice and information for workers in the statutory sector. The Royal Association for the Deaf, for example, produces a *Quick guide for midwives working with*

deaf parents (www.royaldeaf.org.uk/page.php?id=100267) while DPPI has an information sheet for teachers who come into contact with Deaf parents. This is only one of a number of information sheets produced by DPPI, an organisation based at the National Centre for Disabled Parents, and which provides valuable advice to professionals who may only come across a disabled parent at infrequent intervals during their career.

The Maternity Alliance – now closed because of funding difficulties – has also been an important source of information on the support needs of particular groups of parents for those working in statutory sector. One example is its information sheet, *Successfully supporting parents with learning disabilities* (www.maternityalliance.org.uk/documents/factsheet_successful_support.doc).

4.3 Conclusion

Those working in adults' services and in children's services (across health and social care) often struggle to meet the needs of families where a parent is disabled or has additional support needs. Professionals are constrained by the structures within which they work and are aware of their own needs for access to other specialisms, skills and expertise. In some localities, committed individuals work hard to develop better practice but come up against an inadequate knowledge base to inform best practice, and organisational, professional and financial barriers to family-focused work.

This literature review and our survey of five localities, the subject of Part 2 of this knowledge review, illustrate both what can be done – in spite of these barriers – but also the need for more national support and direction to promote good practice. Without this, services and individual practitioners will continue to experience difficulties in meeting the needs of families where a parent is disabled and/or has additional support needs.

Conclusion

This review of the research literature has identified some major gaps in our knowledge about, and the policy and practice context of, the needs and experiences of parents with physical and/or sensory impairments, learning difficulties, mental health problems, HIV/AIDS and drug and/or alcohol problems.

As Chapter 1 concluded, we do not have accurate or comprehensive statistics of the numbers of parents concerned and attempts to assess the numbers are also significantly hampered by overlapping populations and the fact that many individuals move in and out of having additional support needs during their families' life cycle.

Our analysis in Chapter 2 highlighted major gaps in the policy and legislative framework. This means that the framework itself does not facilitate appropriate responses from those commissioning and delivering services.

Although the legislative framework for adult social care does acknowledge parenting roles, the policy framework fails to treat parenting as a central issue (with the partial exception of that for substance abuse). Inter-agency relationships have been a key issue for adult social care but this focus has not included supporting disabled adults with parenting responsibilities, and the concern expressed by previous generations of policy-makers and commentators about the relationship between children's and adults' services has, to a large extent, fallen off the agenda.

Within the children's services policy and legislative framework, there is very patchy recognition of the need for children's and adults' services to work together (with the exception of the *National service framework for children, young people and maternity services*). Inter-agency relationships are a key issue within the *Every child matters* framework but the focus is almost entirely concerned with children's services in education, health and social care. It would appear that the importance of adults' and children's services working together to address families' needs has, to a large extent, been lost.

Chapter 3 looked at the research evidence about the experiences of families where parents are disabled or have additional support needs. It

concluded that we do not know enough about parents who are not in contact with services, and even among those who are, most of the evidence concerns their experiences of services rather than their needs and circumstances. There are particular gaps in research on the experiences of fathers and on the role of the extended family.

It is clear, however, from the existing knowledge base, that these groups of parents are at disproportionate risk of experiencing barriers to parenting, in addition to any difficulties created by their particular support needs. These socio-economic barriers include poverty and unemployment, poor housing, living in poor neighbourhoods, negative attitudes and discrimination, and unequal access to information. The chapter moved on to look at the evidence of the particular support needs of the parents covered by this knowledge review, at different stages of their families' life-cycle. We drew attention to evidence that many parents experience fluctuating needs, have a range of support needs, and/or experience more than one risk factor. Although there are very few rigorous evaluations of the effects of service interventions, there is a considerable knowledge base of both the difficulties that parents experience in their relationships with services, and what kind of support they value. The chapter concluded by looking at the research literature on children's experiences, drawing on this to summarise both the difficulties that children may have and also at the factors which help to promote their welfare.

Finally, in Chapter 4, we looked at the experiences of services and professionals in their relationships with these groups of parents and at what progress is being made to develop better practice. Generally, both adult's and children's services struggle to respond appropriately to the needs of families affected by parental impairment, illness and/or additional support needs. They are hampered by the fact that the policy and legislative framework does not facilitate joint working across children's and adults' services. The organisational and financial constraints within which practitioners are working make it difficult to provide anything other than fragmented and crisis-driven responses to needs. Our locality survey in Part 2 of this knowledge review identifies the importance of preventative and anticipatory support at different levels of needs and in varying circumstances. The best practice in the five localities, and also evident in some of the examples discussed in Chapter 4 of this literature review, addresses both disabling barriers *and* needs relating

to illness, impairment or substance abuse, in ways which respond to the immediate needs of parents and their children *and* prevent further problems arising.

This literature review has identified a need for government, mainstream services, and specialist adults' and children's services to address more effectively the needs of families where a parent is disabled or has additional support needs associated with illness or substance misuse. These families account for a large proportion of the 'vulnerable children' targeted by so much of current government policy. Their experiences and needs are crucial to the general aim of improving the life chances of children and young people and delivering equality of opportunity, as set out most recently in *Support for parents: The best start for children*.³⁶¹ Unless these parents receive equal access to the interventions and support associated with this strategy – from policies aimed at halving child poverty by 2010 to the piloting of parent support advisors – the government will have difficulty meeting its aim of improving outcomes for children. Unless local services – both mainstream and specialist – are assisted to develop better practice by a more rigorous knowledge base, and by national direction and local commitment to address organisational and financial barriers, practitioners will continue to struggle to meet the needs of these parents and their children. Most importantly, too many individual parents and children will continue to be denied a secure and sustaining family life.

Good practice survey

6.1 Summary of key messages

The good practice survey addressed the key questions of:

- - What are the conditions that promote effective working in support of disabled parents:
 - > across adults' and children's social and health care services?
 - > between all relevant agencies in the statutory and voluntary/ community sectors?
- - How can good practice be promoted?

6.1.1 Good practice promotes parental independence and children's welfare

Good practice ensures that:

- - parental support needs that adults have or may have in the future are assessed and addressed as a matter of course with the involvement of appropriate specialist services
- - there is recognition that if parenting needs are assessed and responded to in good time within the adults' social care framework, children are less likely to be in need
- - where there is concern for children's welfare (including cases where children have been removed from home) children's services work in partnership with the relevant adult social care specialisms
- - disabled parents' needs are routinely addressed within mainstream services such as education, health and parental support.

6.1.2 Good practice aims to prevent avoidable difficulties from arising

Good services make support available across the range of impairments and health-related situations and across a spectrum of levels of family need so that children's welfare and parental independence are optimised. To realise this goal, the following practical measures are necessary:

- - Eligibility criteria must be changed to take parenting needs into account so that responses can be put in place at lower levels of need than are currently recognised within specialist adult disability services.
- - Clear policies and procedures are needed to enable an effective joint response across services and agencies (including those in the voluntary sector).
- - Joint commissioning and joint working should take place so that flexible, ongoing support that can respond to changes to both impairment/illness and family circumstances is provided.
- - Anticipatory mechanisms should be put in place to promote resilience and build parents' ability to cope with future challenges.

6.1.3 Good practice is responsive to the experiences of disabled parents as service users and gives ongoing attention to issues of access and approachability

The good practice survey collected a great deal of information about what makes it possible for parents, children and family members to feel comfortable in approaching support services. Parents who are currently using services and parents who have succeeded in raising children offer a valuable resource in developing services that are approachable and supportive. The parents who participated in this knowledge review identified characteristics of good support. They said that good services :

- - are offered in time to prevent unnecessary difficulties
- - include fathers as well as mothers; grandparents and other kinship carers, foster and adoptive parents, as well as natural parents
- - respond flexibly and quickly to changes in family situations
- - are responsive to cultural needs and preferences

- - provide access to parenting support without the automatic involvement of children's services
- - do not leave family needs unmet because they fall between administrative categories
- - do not pass parents between agencies and service divisions to avoid cost
- - provide information and support in ways that are easily understood, as well as assistance and/or advocacy support where necessary.

6.1.4 Good practice involves joined-up working across agencies and service divisions

Services and agencies concerned with adults and with children have to be in a position to work together effectively across varying timescales, budgetary frameworks and organisational structures while at the same time working to distinct and overlapping legislative imperatives. Cooperative working is facilitated by:

- - the development of clear protocols, jointly owned across relevant agencies in the statutory and voluntary/community sectors, which outline general and specific procedures for liaison, information sharing, joint working and cost sharing
- - increased clarity about the roles and responsibilities of other professionals, resulting in greater levels of trust and enhanced ability to make appropriate referrals and use of available resources
- - the appointment of managers in facilitating liaison across service divisions and agencies in delivering services to disabled parents
- - flexible, responsive arrangements for budget sharing across agencies and service divisions.

6.1.5 Good practice is sustainable

For good practice to be sustainable it needs to be embedded in service structures and cultures, securely financed and supported by the commitment of decision makers. Sustainable, good practice is backed by:

- - the capacity to make informed decisions about service development based on robust evaluations of interventions across cost centres

- - the engagement of service leaders and local politicians and the integration of disabled parents' issues into local priorities, targets and strategic initiatives
- - an ongoing culture of training across all levels of personnel in relevant agencies in relation to disabled parents' issues
- - ongoing representation and input across the range of parents who are being supported, including the participation of experienced parents and those currently using services.

6.1.6 Promoting good practice

The relationship between national direction setting and the local development of policies and protocols was explored. The good practice examples we looked at suggest that local protocols arise out of particular contexts, address specific difficulties that have arisen, and, at the same time, bring about a degree of commitment on the part of participating parties to following the procedures agreed. There was also a broad consensus that national direction, policy drivers and practical incentives would help to indicate the importance of disabled parents' issues to local authorities and relevant agencies and encourage the setting of national and local targets in relation to disabled parents.

It was felt that making examples of good practice such as protocols and policies that have been produced locally more widely available and sharing (specific) information and resources would help in promoting the spread of better practice in supporting disabled parents.

6.2 Introduction

6.2.1 A time of challenge and opportunity

The range of parents included in this SCIE knowledge review is deliberately broad and inclusive. It includes parents who may have additional requirements related to physical and/or sensory impairments, parents with learning difficulties, parents with mental health, drug and/or alcohol related difficulties and those with serious illnesses, including HIV/AIDS. It includes Deaf parents and others who may or may not identify with the term 'disabled'.

The accompanying review of research and policy literature shows

that the additional requirements of these parents in relation to parenting are insufficiently addressed and met by either universal or specialist services. The review discusses a number of policy developments that have a far-reaching impact on the development of services to all families. It also outlines a number of gaps in research, policy and service provision in supporting adults with additional support needs in their parenting role. Because of disability-related prejudice, social and economic disadvantages, and the way that services are organised and delivered, services have frequently been less accessible to these groups of parents. Moreover, there are barriers to children's and adults' services working together to promote good outcomes for families.

As restructuring takes place around the development of new philosophies, there is a danger that existing gaps in services to disabled parents, their children and other family members will widen unless opportunities to promote new ways of working consciously include them. New directions in policy and extensive restructuring in adults' and children's services across statutory, voluntary and community sectors create timely opportunities as well as challenges.

6.2.2 Outline of the good practice survey

Chapter 7 sets out the background to the good practice survey and identifies the key informing question. The rationale behind the selection of the five good practice examples and the way in which information was collected are described. Chapter 8 outlines the work currently being developed in each place, including particular issues highlighted in our discussions.

In Chapter 9 we describe the characteristics that were evident in all the good practice examples and explore the underlying commitment to preventing avoidable poor outcomes and supporting families. In Chapter 10 we discuss increased recognition that responsibility for children's safety and their well-being in the context of families is a shared responsibility across statutory services, together with organisations in the non-statutory sector. We discuss the implications of this for multi-disciplinary and inter-agency working in support of the parents covered by this knowledge review. In Chapter 11 we highlight messages about making information accessible to disabled parents and explore what makes services good from families' point of view. We look also at some

of the practical issues around involving parents in developing services, including those who are currently service users and those whose views are seldom heard. In Chapter 12 we draw out some of the lessons learnt about how good practice can be sustained and some of the barriers local authorities have experienced in implementing good practice in services to the parents covered by this knowledge review. Finally, we explore the relationship between local and national contexts in the endeavour to ensure that good practice becomes more widespread. We conclude with what we have learnt from the survey about putting appropriate systems and resources in place to support parents with a range of requirements at various levels of family need.

Background to the good practice survey

7.1 Key questions for the survey to answer

The stakeholders we consulted agreed that the survey of good practice should be informed by the following central questions:

- - What are the conditions that promote and the barriers that impede effective working in support of disabled parents:
 - > across adults' and children's social and health care services?
 - > between all relevant agencies in the statutory and voluntary/ community sectors?
- - How can good practice be promoted?

It was agreed with the stakeholder advisory group that 'effective' should be defined. We agreed that for the purposes of this survey effective working should:

- - promote parental independence and children's welfare
- - prevent more serious problems arising
- - be acceptable to parents, family members, children and professionals
- - be sustainable (that is, embedded in service structures, long-term budgetary arrangements and ongoing training).

It was also agreed that a particular focus of the survey should be to look at the tools required for the development and sustainability of good practice at a time of organisational change.

7.2 Selecting the good practice examples

7.2.1 Background

In the late 1990s, when the then Social Services Inspectorate (SSI) carried out a national inspection of services to support disabled adults in their parenting role, only one of the eight local authorities inspected had adopted policies aimed at meeting the needs of disabled parents.³⁶² The Joseph Rowntree Foundation (JRF) subsequently established a task force on supporting disabled adults in their parenting role and commissioned a survey of all English local authorities in 2000. One in four local authorities had policies and/or protocols about providing support to disabled parents, although most were in draft or in the early stages of use, while almost another one in four local authorities were undertaking work or had plans to do so.³⁶³

Following publication of the SSI inspection report and the 2002 survey, the JRF task force and the research organisations Making Research Count and Research in Practice organised a series of workshops to help implement good practice that was informed by these earlier initiatives.* Attendees at the workshops confirmed what both the SSI inspection and the 2002 survey suggested – that the aspiration to improve support services to these groups of parents is proving difficult to translate into practice. Moreover, there was concern that the situation might worsen rather than improve as services to adults and services to children move further apart and while the cooperation between the two in delivering services to parents with additional support requirements is not an issue that local authorities are required to consider.

A survey of local authorities in Wales and Northern Ireland carried out for this knowledge review (to supplement what we know of the situation in England) had a poor response rate (44 per cent) in spite of telephone follow-up. Of those responding, 12 out of 16 local authorities had no policies/protocols covering any of these groups of parents. Of the four that had policies/protocols, all four had policies/protocols concerning parents with physical and/or sensory impairment, and all four also had

* See Appendix for details of an article about the Making Research Count seminars (Crawshaw and Wates, 2005).

policies/protocols covering parents with substance misuse problems. Three had policies/protocols concerning parents with mental health support needs and one covered parents with learning disabilities.

In addition to these policies/protocols, 12 of the Welsh local authorities provided examples of work to develop service responses aimed specifically at one or more groups of parents covered by this knowledge review. Four authorities in Northern Ireland sent information about protocols which, while they were not aimed at parents with additional support needs, were said to be adapted on a case-by-case basis to meet the needs of disabled parents, as illustrated by the following comment:

‘The service is designed primarily to meet the needs of children who are ill or who have a physical/sensory disability. However, it can be extended to include children whose parents are ill/disabled, especially during difficult stages of an illness or in an emergency.’

7.2.2 Selecting examples

The selection of good practice examples was informed by:

- - the 2002 survey of English local authorities
- - feedback from the local authorities participating in the Making Research Counts/Research in Practice workshops
- - the survey of Wales and Northern Ireland carried out for this knowledge review.

Members of the stakeholder group advising the project also made recommendations of good practice.

We agreed with the stakeholder group that for the purposes of this survey effective working should:

- - promote parental independence and children’s welfare
- - prevent more serious problems arising
- - be acceptable to parents, family members, children and professionals
- - be sustainable (that is, embedded in service structures, long-term budgetary arrangements and ongoing training).

The literature review carried out for this knowledge review illustrated that support that is aimed specifically at parents with additional support needs and that meets good practice criteria is neither widespread nor well-established. This inevitably had implications for our selection of good practice examples. We had hoped to include work that was well established and firmly embedded in ongoing structures. In fact, much of the good practice we could identify was in the early stages of development. Moreover, the restructuring of adults' and children's services has created additional challenges for the development and sustainability of good practice. The implications of this are explored in the final chapter.

The developmental nature of much of the work described had particular implications in terms of issues of diversity. We were not able to identify among the good practice examples work which specifically focused on black and minority ethnic disabled parents and children (or other minority groups) and none of the services we looked at had focused specifically on these issues. Areas in which two of the good practice examples are based have above average populations of black and minority ethnic populations: 41 per cent in Greenwich and 12 per cent in Cardiff (the national average is 7.9 per cent), although this issue was not raised in any detail in the context of our interviews or meetings or in the documentation the projects provided us. However, some projects did intend to consult with black and minority ethnic parents. Our consultation with black and minority ethnic disabled parents has given us an important opportunity to highlight the issues they raised but, in general, much work needs to be done concerning diversity issues and disabled parents. This is reflected in the limitations of our identification of good practice.

A further limitation was the degree to which the localities selected represent a geographic spread, particularly as we were not able to identify a good practice example from Northern Ireland. It became clear that to describe good practice across the broad range of specialist areas covered by this knowledge review, a degree of compromise was necessary.

It also became clear that while effective working should 'prevent more serious problems arising', it could also apply at different stages at which service providers are involved with parents. While all the work considered in this good practice survey can be described as 'preventative',

this can mean very different things in different contexts and in different family situations.

The examples of effective preventative intervention included:

- - preventing harm to children when families are passing through times of crisis, including cases where there is an imminent possibility of children being removed from home
- - post-crisis support aimed at anticipating and building a family's ability to cope with future challenges
- - addressing specialist low-level parent support needs for information, equipment and assistance.

These examples cover a continuum of preventative intervention and it is clear from the services we looked at that effective support is possible across such a continuum.

We chose five good practice examples in Norfolk, the London Borough of Greenwich, Cardiff, Stockport and Cheshire. In spite of the limitations on the examples available, the five that were selected illustrate both the opportunities for, and the barriers to, delivering effective services.

7.3 Collecting the information

Focus group meetings were held with key agencies and individuals from each of the five local authorities in which practice was selected and relevant documents were gathered from each service or group. An information schedule was used, but meetings did not follow exactly the same format for each place as work was at different stages of development.

Wherever possible meetings involved personnel from both adults' and children's health and social care services, as well as both statutory and non-statutory agencies. In discussions with three of the projects (Cheshire, Norfolk and Stockport), disabled parents were also involved. Two discussions involved parents with learning difficulties and in another parents with learning difficulties met with the interviewer for a separate discussion. The Option 2 project in Cardiff, which works with parents with drug and/or alcohol problems, has a policy of not involving parents who have used the service directly in service development and training. However, one of the consultation groups that we held involved

parents using an alcohol abuse support project and their perspective has helped inform the practice survey. Our consultation with a group of children who have disabled parents helped to inform both the literature review and this good practice survey although children were not involved directly in any of the discussions that took place in the five selected localities. The needs and views of children were described as being of great importance to much of the work that was being developed, whether this related to safeguarding and promoting children's welfare generally or a specific focus on young carers.

The opportunity for people working in different agencies to meet and reflect on developments was welcomed by participants, and in some cases the discussion was combined with taking the opportunity to progress work that was ongoing. For example, the discussion in Norfolk was combined with the first official meeting of the recently formed parents' reference group and representatives from social services. Notes of the meetings were sent back to all participants for comment and points of clarification were pursued through email and telephone discussions. Participants were also given the opportunity to comment on an early draft of this report.

The good practice examples

The discussions with representatives from the five good practice examples are explored thematically in Chapters 9, 10 and 11, but a brief description of each is provided below.

8.1 Norfolk County Council: Enabling parents with a disability or long-term illness protocol

- - In April 2000 a senior manager in Norfolk children's services was commissioned to introduce the *Framework for the assessment of children in need and their families* in Norfolk. The authority also recognised a need to address problems highlighted in *A jigsaw of services*,³⁶⁴ the SSI's report on supporting disabled adults in their parenting role.
- - Both documents stress the need for more joined-up working across service divisions and agencies to support parents. It was decided to prepare a protocol and policy.
- - *Fair access to care services*³⁶⁵ provided guidance to local authorities on eligibility for adults' services. This guidance specified that parenting needs should be included in assessments for adult community care services.
- - Further developments in children's services that are central to the Norfolk initiative include *Every child matters* and the Children Act 2004, with their emphasis on agencies working together to deliver child-focused and early interventions.
- - Children's managers are aware of the need to make sure that work with disabled parents is included in the logging of non-governmental sector work being carried out across Norfolk as part of its children's plan.
- - In Norfolk, as in other local authorities, adults' and children's social services are now organised separately. Children's services are aligned with education under shared direction, while adults' social services are organised more closely with health, housing and other adults' services.

- - In addition to these policy and structural prompts, work to improve services in Norfolk has been spurred on by concerns about particular situations where it was evident that better coordinated and more effective support for disabled parents was needed.
- - Norfolk County Council decided that if it was serious about introducing the new protocol, someone should have specific responsibility for promoting its use across the county.
- - A manager was seconded to the post for six months full time and six months part time. Her task has been to oversee implementation of the policy and protocol, making sure that other relevant work in the authority is compatible. She has worked mainly with statutory services but also with the voluntary/community sector.
- - Senior managers regard this dedicated role as an essential part of changing both practice and mindsets. Obstacles to progress can be addressed, queries answered and signposts given to further advice and resources (including legal advice where appropriate).
- - A disabled parent activist in Norfolk involved in developing the protocol from the outset has, at the request of social services, established a reference group which is composed of parents with a range of additional support needs. Parents contribute both as individuals and as representatives of a number of organisations. The parents' reference group will inform the work at each stage of development and evaluation.
- - The directors of both children's and adults' services have committed to the 'Norfolk protocol for enabling parents with a disability or long-term illness'.
- - The intention of the protocol is to monitor spending across services on support for disabled parents so that informed decisions can be taken at a politically significant level locally on the development of coordinated budgets and inter-agency training.

8.2 London Borough of Greenwich: CAPE project

- - Greenwich is an area of high deprivation. An independent review following two child deaths showed that the needs of some families with parents who have serious mental health problems were not being met either by specialist mental health services or by children's services. It

highlighted the need for increased liaison between the two for these families.

- - The Gatsby Charitable Foundation is funding CAPE, a three-year project, to work with families in which a parent or carer has mental health problems. Many of these families are involved with services but have family support needs that are not currently met by either health or social services. This includes children and parents whose needs do not reach the high eligibility thresholds for either children's services or adult mental health services.
- - Over the past two years a liaison and development worker, paid initially from Neighbourhood Renewal Unit funding, has been working across Oxleas Health Trust and Greenwich social services and has been jointly managed by both agencies.
- - During the time she has been in post, the liaison worker has worked with professionals (including adult mental health services, hospital-based psychiatric services, children's social services and maternity services) to develop joint procedures and to improve their understanding of one another's roles.
- - Protocols and flow charts outlining general procedures for inter-agency working, eligibility criteria for receiving services and contact details for different agencies have been produced. Documents which address specific interface issues have also been produced..
- - A shorter leaflet sets out information written specifically for parents with mental health problems.
- - An inter-disciplinary team is being set up that will initially consist of three or four practitioners, with plans to increase staffing as the project progresses and in response to specific needs. Adult mental health services and/or children and family services will manage cases but the CAPE project will be commissioned by them to work with families on a short-term focused intervention basis to achieve specific goals.
- - Referral forms require adult mental health or children and family workers to be specific about the intended aims and outcomes of the short-term interventions and the follow-up care plans.
- - CAPE hopes to work on a short-term individual basis with parents and children. It also hopes to work with groups of parents.
- - Experience suggests that child protection conferences can sometimes be avoided if there is a plan that all parties agree to. The liaison

worker in Greenwich draws on experience of pre-birth planning from her previous work in hospital-based child protection. She sees pre-planning as a way to avoid family crises.

- - As well as funding CAPE, the Gatsby Charitable Foundation is also providing The Family Welfare Association's Building Bridges project in Greenwich with funding for two complementary posts (one to work with pregnant women and new mothers and the other to support families in which a parent or carer has been admitted to hospital). The Building Bridges project may continue to work with families after the CAPE team has addressed immediate concerns so that problems are less likely to recur.
- - The project has a budget for evaluation which is important to ensure that good practice will be evidence-based and sustainable in the long term.

8.3 Cardiff: 'Option 2' project

- - The 'Option 2' project has been running for six years in Cardiff and the Vale of Glamorgan with two full-time therapists in each place and a shared administrative assistant. The cost of each of the projects is approximately £80,000 a year, including salaries, transport costs and supplies. These costs are met jointly by the Welsh Assembly Government and the Home Office, with the additional cost of premises met by the social services departments in both councils.
- - The project works on a crisis intervention basis with families where there are serious child protection concerns related to parental drug and/or alcohol problems. Therapists aim to help parents recognise that they are in crisis and that change is needed to keep their families together.
- - Parents cannot self-refer. However, parents who have used Option 2 are recommending the programme to other parents who they know are struggling. If a family then approaches Option 2, the team may ask a social worker for a referral.
- - A safeguarding 'safety plan' is put in place while therapists undertake four- to six-week crisis-led intervention with the families. The therapists work with one family at a time and make themselves available to that family 24 hours a day, seven days a week. The aim is to create

a positive change in the way that families function, enabling children to remain safely at home if possible.

- - Therapists work with families to help them to focus on what is working, to identify their hopes and goals for the near future and to support them in taking a series of structured and monitored steps to achieve their goals.
- - A children's social worker has responsibility for a case throughout the intervention period and keeps in touch with the therapist, resuming the casework at the end of the project.
- - Records about the family, including all reports and correspondence, are shared and discussed with families. The records reflect the strengths and aspirations of family members as well as their difficulties.
- - Following the intervention period the Option 2 therapist meets with a family at intervals throughout the year to evaluate progress towards the family's goals. At these times the therapist will usually contact the family's social worker before and after the visit. Reports on the work done with Option 2 form part of the assessment process.
- - A family that has worked with Option 2 can ring at any time to ask for help and the project will provide 'booster' sessions. These may also be undertaken at the request of the social worker. A new referral would be required in the event of a further crisis requiring another full intervention.
- - Families involved in the project have typically maintained positive progress in relation to their goals throughout the year following the intervention. The project has had good success in preventing children being removed from home over the three-year period in which families have been monitored. Option 2 is hoping to establish wider measures of family cohesion that can be validated independently.

8.4 Stockport Metropolitan Borough Council: Community Team for Parents with Learning Disabilities

- - Following concerns about lack of coordination and support in relation to some cases of parents with learning difficulties, a multidisciplinary steering group met at two-monthly intervals over a period of two

years to develop a clear diagrammatic 'pathway' for inter-agency cooperation in supporting parents with learning difficulties.

- - The group consisted of representatives from the community learning disability team, the children's social work team, the midwifery service, the education service health visitors from the local primary care trust, and the teenage pregnancy coordinator from Stockport social services.
- - There was also representation from agencies in the voluntary/community sector, including the local advocacy service. The advocacy worker facilitated two-way communication between the steering group and a group of parents with learning difficulties.
- - The 'pathway' developed by the group has been piloted and refined to reflect practice and legislation. Various pieces of legislation and guidance have been used to show that adults with learning difficulties are entitled to support with their parenting role in their own right without their children being identified as children in need.
- - Once the pathway for inter-agency cooperation was in place, there was an increase in the number of referrals received by the steering group to work with new and prospective parents. In response to this increased demand, the group made a successful application to the Stockport Learning Disability Partnership Board to establish the Community Team for Parents with Learning Disabilities, comprising an adult learning disability social worker, a support worker and a community nurse.
- - The team aims to enable parents with learning difficulties to be as independent as possible and provides ongoing and anticipatory support as needed. Short-term crisis intervention with families is followed by ongoing contact to prepare parents for the next stage of parenting and to help parents anticipate and prepare to meet further needs as they arise.
- - Frequently new and prospective parents are linked with other agencies and resources, often in the voluntary/community sector.
- - The team works closely with children's services when core assessments are conducted to ensure that information and questions are adapted and presented in an accessible format.
- - The team tries to ensure that information about parenting is available in an appropriate format and that parents have access to suitable skills training.

- - The original inter-agency steering group does not meet currently but the intention is that the services concerned should meet as and when necessary to create protocols on specific aspects of inter-agency practice. Two areas already identified are the housing needs of parents with learning difficulties, and work across children's services and community care services. This joint working will be all the more crucial when the children's and adults' services move physically apart in the course of the next year.
- - Like Option 2 and CAPE, Stockport's Community Team for Parents with Learning Disabilities works with parents who are in imminent or longer-term danger of having children removed from home, though it is not a requirement that families be known to social services. Indeed, in this project, families may self-refer to request support, or simply take the opportunity to be part of the parents' group. The majority of support provided to families by the team is funded by Supporting People. The team is currently working with a local voluntary agency to make a case for ongoing funding.

8.5 Cheshire County Council and disabled parents' group

- - Following an extended peer research and development project funded by the Children's Fund, a local group of disabled parents produced the *Parents' assessment toolkit* designed to help parents navigate the process of being assessed for services.
- - The parents involved in the project felt that the toolkit could be a useful resource for priming parents ahead of assessment. It may also give parents a greater sense of ownership in their relationship with social services.
- - In 2005 the parents' group held two training events for the voluntary/ community sector and for local authority personnel to launch the toolkit. They may also hold a further workshop to introduce the *Parents' assessment toolkit* to health workers.
- - Prompted by the parents' initiative, social services revisited a lapsed initiative to develop services for disabled parents. A joint adult health services and social services protocol had been prepared following the SSI's report in 2000, *A jigsaw of services*,²⁸⁰ and had been re-examined following the publication of *The right support*¹⁹⁹ in 2003 (the final

report of the Joseph Rowntree Foundation task force on support for disabled parents). In 2004 a social services manager again looked at the protocol and found that a county-wide group which had been set up to develop services to disabled parents had lapsed while other related groups continued to meet 'but not in a coordinated way'.

- - The current intention is to create a new county-wide strategy group, to be informed by local area groups and to involve the voluntary/community sector and a range of disabled parents. The group will develop an inter-agency approach to supporting disabled parents.
- - Although this work is at an early stage of development and it is not possible to say how it will operate in practice nor how it will be funded, it is none the less valuable to include it in the good practice survey because of its significance as an attempt to integrate work done by a group of parents into the local authority's own emergent plans.
- - Adult health services and social services in Cheshire are currently restructuring and moving closer together. There is creative thinking about how work can best be resourced and monitored across social services and health and how to make use of the opportunities to develop coordinated support for disabled parents.
- - Health and social services have created a joint local performance target on health and community well-being, which is one place where the development of services to disabled parents might be examined.

There is recognition of a need to increase the exchange of information between social services, health and the voluntary/community sector and an interest in exploring the role of direct payments in supporting disabled parents.

A shared philosophy

‘It’s in the child’s best interest to be with their parents, that’s what the children want, that is what everyone wants, if those parents can parent adequately with support.’

Adult social worker, Stockport Community Team for Parents with Learning Disabilities

9.1 Promoting children’s welfare by supporting parents

The good practice examples selected for this practice survey share a philosophy: they all promote children’s welfare and family sustainability through positive engagement with parents and by seeking to overcome the potential disengagement of families with services at whatever stage support agencies become involved.

In all the good practice examples, engagement has been facilitated by the involvement of service users in the development and evaluation of practice and through agencies working together in a coherent, co-ordinated way to prevent poor outcomes. This is done by providing appropriate support and resources to prevent problems from arising or, where problems have arisen, to restore and maintain successful parenting. In achieving this, there is a conscious goal of working effectively across agencies in both the statutory and voluntary/community sectors.

Personnel working in both the statutory and voluntary sectors explained that increased awareness of the need to share the responsibility for safeguarding and upholding the welfare of children has led to a recognition of the need to develop a range of early support for families. Local pressures to improve services have included instances where things have gone wrong and in response to parents reporting their dissatisfaction with the lack of available support.

Parents stressed that support needs to be readily accessible and that they need to feel safe to seek information and help before avoidable difficulties arise or family problems become severe.

9.2 A spectrum of support strategies

The range of good practice examples included in this knowledge review illustrate the need to develop diverse support strategies that are able to respond to families' needs at different times and in different circumstances. There was recognition that looking for ways to minimise harm to children and provide support to parents remain key issues, whatever the nature of the intervention. At whatever point the work takes place, the intention is to provide appropriate support to parents.

The practice examples we looked at cross the entire spectrum of preventative strategies, ranging from supporting disabled parents in carrying out their parenting role without unnecessary problems, through to crisis intervention and supporting families in critical situations. At all points on the spectrum work aims to help families to anticipate further needs and improve their ability to cope with future challenges.

9.3 Supporting disabled parents at an early stage

Although it is generally agreed that the best way to support children is by supporting their parents appropriately and in good time, both parents and professionals identified that the way services are organised and delivered can militate against this. Moreover, it was acknowledged that involvement with children's services can be perceived by parents as inherently judgemental and stigmatising and that this can, in itself, act as a barrier to service providers working in partnership with parents to promote the best possible outcomes for children.

Workers in both children's service teams and in specialist adult teams recognised that the use of terms such as 'child in need' can appear to parents to reflect assumptions about parenting capacity. This in turn can prevent parents seeking support that might otherwise be helpful. Professionals stressed that it is essential to get the right messages across to parents: an adult social work manager in Cheshire said, 'It makes all the difference whether parents see us as being there to help them or to judge them'.

Members of the Community Team for Parents with Learning Disabilities in Stockport were concerned that their original diagrammatic 'pathway' for inter-agency liaison was built on the assumption that the children of parents with learning difficulties had to be identified as children in need before their parents qualified for support. Various pieces of legislation and guidance were used to show that adults with learning difficulties are entitled to support with their parenting role in their own right without their children necessarily being identified as children in need. The pathway was changed accordingly.

Many parents reported that very high thresholds of difficulty have to be reached before a service is provided. A visually impaired mother participating in one of the discussions, who had at one time approached social services for help, felt that the message to her had been, 'Come back when you are at breaking point'. Not only did she find this undermining of her efforts to seek support in good time in the interests of her children, she also considered it an unsound financial judgement on the part of services, for, as she pointed out to social workers present at the meeting, 'When I get to breaking point it is going to take a lot more of your money to straighten me out'.

It is generally acknowledged that an effective way to support children is to support their parents. However, as one adult service manager said, 'When money gets tight the response is generally to raise the barriers that determine who will get services and who will not'. Managers of services for disabled adults expressed the view that this does not fit well with the *Fair access to care services* policy guidance.³⁶⁹ This guidance states that local authorities should provide services to prevent problems arising for parents. The manager appointed to oversee the implementation of the Norfolk protocol pointed out to her colleagues that, when the needs of a child are considered alongside the needs of the disabled adult as a parent, this will often be sufficient to lift parents who might not otherwise qualify for services 'over the barrier'.

Service providers agreed with parents that responses to disabled parents need to be more consistently supportive, rather than patchy and crisis-driven. Both parents and professionals felt that this will call for ongoing training across different agencies, involving specialist adults' services, children's services and the voluntary/community sector.

9.4 Anticipating and, where possible, avoiding crises

The importance of translating the philosophy of prevention into real and tangible services for disabled parents was underlined by parents themselves, both in the discussions that took place in the good practice localities and also in the consultation groups. Many times parents said how it was unacceptable that their families should have to reach some kind of social, emotional or medical crisis point before access to services is triggered.

Sometimes, unfortunately, the work that ends up being done in a crisis could and should have been done much earlier. For example, the Community Team for Parents with Learning Disabilities in Stockport find themselves working on basic skills, such as maintaining a routine, budgeting, debt management, healthy eating, hygiene, cookery skills, and children's health, with parents in immediate danger of having children removed. Parents with learning difficulties often did not have access to this information when it could have made a major difference to assessment of their parenting capacity.

Recognising this, the team has developed a style of working that is anticipatory, looking ahead with parents to avoid crises that arise because parents do not have access to basic information and skills training. It is integral to their work with parents with learning difficulties that support is not viewed as a 'once and for all' process, but is ongoing.

When the Stockport team's intensive short-term work with parents in crisis comes to an end, it is often relevant to refer them to other ongoing support services, which may be located in the voluntary and community sectors. However, the team are clear that they are not ending their relationship with families. As the specialist social worker said, 'You don't suddenly wake up and not have a learning disability. We have a mindset within adults' services – we are generally there for life'. The team may find itself working with parents to find solutions to a range of difficulties that arise, for example with skills training needs, adequate housing, debt management, relationship difficulties and so on.

This raises again the question, discussed in the previous section, as to how support services aimed at preventing poor outcomes can be put in place where parents do not meet the high threshold criteria for receiving services from adults' services and are not currently experiencing the level of need that would bring them to the attention of children's services.

Organisational shifts in response to changing national and local priorities are a further potential threat to preventative work with families whose needs are not so immediately serious. A number of reasons for this were discussed at the meeting with the CAPE project in Greenwich. The children's social worker present expressed the view that as children in need teams in children's social services hold cases for longer, they are carrying out the kind of 'heavy end' work previously done by family assessment centres. In consequence, children's services are doing less short-term, prevention-focused intervention and are frequently only working with families 'on the verge of child protection proceedings'. Although Greenwich has seen an increase in the number of children on its child protection register it was suggested that many of them are on the register for a shorter time than previously and that there tends to be 'a good plan in place' at the point that children are removed from the register. There was felt to be a need to replicate this planning for families at lower levels of need to prevent avoidable problems worsening.

Learning about other professionals' roles across children's and adults' services and across the statutory and voluntary/community sectors was seen as an important role in early intervention and preventative support. It was also seen as contributing to more effective safeguarding procedures, since people who understand each other's roles are more confident and more competent to make appropriate referrals. Moves to develop multi-professional, inter-agency working are discussed in the following chapter.

9.4.1 Supporting families in crises

In three out of the five good practice examples, the death of a child or children known to services was the incentive for re-examining services and the relationship between adults' and children's services in particular. In another area, the incentive had been a contested child care order which could have resulted in a baby being permanently removed from its parents. This case had a major impact on the working relationship between children's and adults' services. As the social worker for adults with learning disabilities said, 'I think ... there needs to be huge lessons learnt from that because if we weren't involved ... that child would have gone, they [the parents] wouldn't have been strong enough in their own

right to have their voices heard and there is nobody in there observing that fact'.

The stakes could not be higher at times. At the same time, pressures upon professionals and parents alike to concentrate on avoiding crises rather than on early intervention were potentially counter-productive. 'Anxious people make anxious decisions', the assistant project manager at the meeting in Greenwich said of professionals who make severe decisions in a crisis that could have been avoided by earlier intervention. In our consultation with parents affected by drug and/or alcohol problems, one mother said that her children's biggest fear had been the thought of being separated from their parents: 'It causes anxiety for children and adults alike to have the fear of separation hanging over them and makes families very wary at times of social services.'

However, when parents in a crisis situation can see that professionals are working together with them and with each other to help resolve difficulties and keep their family together, their responses are often positive. Support workers at the CAPE project in Greenwich reported that parents are often very relieved to think that they might get some support with their children. Parents have had particularly positive responses to interdisciplinary meetings aimed at putting support in place as an alternative to calling a child protection conference.

The Option 2 project in Cardiff works exclusively with families that are close to having children put on the child protection register or removed from home altogether. Parents generally recognise the seriousness of their situation and therapists see it as part of their role to help families see a way through the crisis so that they can make a clear commitment to doing whatever needs to be done. There is a commitment to transparency and open communication with all records shared with parents.

The role of the project therapist varies, depending on the family's situation and the goals that they have set themselves. Workers are available day and night and can find themselves being called upon to do anything from counselling someone who is suicidal, through to motivating a family to decorate their front room if that is what the family feels is needed to help to move things forward at a given moment. Unlike CAPE in Greenwich and the team in Stockport, Option 2 has not developed formal protocols with other agencies, although there is an agreement in place that parents involved in the project may be fast-tracked for programmes to eliminate drug or alcohol use if that is the course of action

that parents have prioritised. The therapists find that they draw on a very wide range of supports across statutory services and the voluntary sector depending on what individual families require.

Families who have worked intensively with the project previously can make contact at any time to ask for 'booster' sessions to prevent recurrence of the crisis situation. These may also be provided at the request of the family's social worker.

9.4.2 Supporting parents whose children have been removed from home

Managers at the Stockport Community Team for Parents with Learning Disabilities believe that 'no child should be accommodated without an appropriate intervention' to support parenting. An essential element of their approach is the idea that there is no cut-off point at which parental support becomes irrelevant and therefore ceases to be considered.

The issue of support for parents whose children have been removed from home is often complex but may be crucial none the less. For example, the Stockport team is very aware that parents with learning difficulties may need more contact time with children who have been removed from home than is generally allowed so that they have time to learn and to demonstrate that they have acquired the skills that they have been assessed as needing in order to parent successfully. This is particularly important where support to learn such skills has not been available before. The team recognises that this will require a fine judgement since it is not in children's interests for their parents to have an extended assessment period if there is little chance that they will be returning to their parents at the end of it. This is one of many examples where it is important that the efforts of adult specialists and children's services are closely coordinated. 'We work in partnership with children's services to maximise learning opportunities during contact sessions with children who are being looked after by the local authority' (Community nurse, Stockport Community Team for Parents with Learning Disabilities).

A children's social worker in weekly contact with the community team emphasised the importance of trust and good ongoing communication: 'We have regular reviews; we communicate very freely and very regularly'. Workers from the team attend core group child protection meetings and, when working jointly on a case, the adult services worker

often takes the role of key worker for the parent to facilitate a good relationship and good communication between services and parents..

Where child protection concerns dictate that children's services take the lead, CAPE project workers in Greenwich were clear that this should not result in adults' services backing out. If anything, maintaining the involvement of adults' services is regarded as crucial at such times. Whatever happens, it is essential to specify who takes the lead in supporting parents and to ensure that appropriate specialist adults' services remain involved.

9.5 Post-crisis support aimed at anticipating and preventing future difficulties

The work done in Cheshire, in Stockport and in Greenwich reinforces the links between work that is done in crises and work that is done to anticipate and prevent further crises. Prevention is not something that is confined to one context but is a consistent philosophy that informs support for parents. Links are made between providing support at a given moment and planning ahead to make sure that unmet needs are met. The team in Stockport emphasised that they saw anticipation as key to helping parents to optimise progress and increase family resilience.

A shared responsibility

‘We will liaise with all relevant agencies, both statutory and voluntary, to safeguard the welfare of the child and to meet the needs of the parents or prospective parents.’

Stockport Community Team for Parents with Learning Disabilities

In Chapter 10 we consider the issue of cooperation and multi-agency liaison across statutory services and voluntary and community sectors in supporting disabled parents.

When in the late 1990s the then Social Services Inspectorate carried out a survey of services that supported disabled adults in their parenting role, they found very little evidence of a coordinated service response to families with dependent children in which one or both parents were disabled, either within social services or across agencies. Furthermore, where innovative multi-agency plans existed, their potential importance for services to disabled parents remained unrecognised.³⁶⁷ A survey of social services’ policies and protocols on support for disabled parents carried out for the Joseph Rowntree Foundation also found that the rhetoric of multi-agency working was seldom translated into tangible measures for disabled parents.³⁶⁸

In the light of these findings, it was agreed by this knowledge review’s stakeholder group that an important dimension in carrying out the good practice survey should be how multi-agency working is operating, what obstacles have been encountered and how these are being addressed.

As explained earlier, the practice examples were chosen among other things on the basis of their commitment to multi-professional liaison and inter-agency cooperation. It was evident from discussions that this commitment had come about in response to a mixture of external pressures (such as legislation, guidance and service policy) and the recognition of a compelling intrinsic need for joined-up services for disabled parents and their children.

10.1 *Every child matters*: shared responsibility for children

The assistant programme manager in Greenwich thought it useful that her appointment to a liaison post with parents who have mental health problems coincided with professionals in both the statutory and voluntary/community sectors becoming more receptive as a result of the lessons learnt from the Climbié inquiry. She thought that the philosophy of *Every child matters* – the idea that nobody should assume that someone else is dealing with a problem within a particular family – is having an effect on practice. Other professionals from a range of backgrounds who were present at the meeting reinforced this perception.

In her experience a much greater range of professionals, including specialists in adult fields such as psychiatry, drugs and alcohol, and HIV/AIDS, and also voluntary sector workers, are now thinking about safeguarding issues whereas before they might not have considered whether their adult clients had children or whether children had parents with mental health needs. This development has had a role in encouraging a wider range of professionals to think about early intervention. This means that they are more willing to be proactive in linking parents with preventative supports.

‘The good thing is that people are not just waiting for social services to pick up the pieces after things have gone wrong ... there is a greater willingness to think in terms of social services as a source of support rather than linking them solely with child protection ... Workers are now getting more confident and saying, “social services can support you” rather than just saying, “I have been told to refer you to social services”.’

Duty manager for community mental health team in Greenwich

Changing attitudes among psychiatrists and other mental health professionals are further helped by the increasing amount of information coming from professional bodies, such as the Royal College of Psychiatrists’ *Patients as parents* report.

This shift towards working with other professional groups to safeguard children who appeared to be exposed to particular risks, and also

to uphold the welfare of children in general, were echoed in the other good practice examples.

10.2 Benefits, barriers, and challenges of inter-agency working

Across the good practice examples surveyed, a number of challenges had been experienced in working more closely with other agencies, particularly at the outset. There was general agreement, however, that these difficulties were outweighed by the many benefits.

10.2.1 Benefits to inter-agency working were seen as including:

- - a clearer understanding of other professionals' roles and perspectives and the development of a mutual working trust
- - greater clarity about agencies' boundaries and a deeper understanding about how each agency might be used to greatest effect
- - increased competence in making appropriate referrals
- - increased readiness to ask whether another service has a contribution to make
- - increased access to a wide range of professional roles and expertise
- - an improved profile for multi-agency teams because of their distinct role in addressing the needs of a specific group of parents
- - identifying and addressing gaps in service provision
- - some parents who are reluctant to approach statutory agencies for help may be more willing to accept support from a non-government organisation
- - working with one group of professionals can be the key to working more effectively with another group.

A useful example of this last point was supplied by the Community Team for Parents with Learning Disabilities in Stockport. They wanted to find a way to support parents with learning difficulties in cases where children's social services had expressed concerns about their ability to prepare adequate meals for their children. The team worked together with the local adult education service to set up a course on cookery and child nutrition suited to the information needs and learning styles of

parents with learning difficulties. Initially, adult education said that the course could only be certificated if it was assessed through written means but the team negotiated and worked with them to devise more appropriate forms of assessment. The parents were then able to return to social services with certificates to show that they had learnt the required skills.

Barriers to inter-agency working have been addressed in the following ways:

- - addressing issues and anxieties around sharing information and maintaining appropriate levels of confidentiality
- - involving people who are in a position to make decisions and people who deliver services
- - identifying resources that can be used to implement and sustain agreed action plans.

A number of challenges were identified in relation to joint working that had yet to be resolved. These included:

- - how to fund and carry out ongoing multi-agency training
- - how to carry out a rigorous evaluation of spending and outcomes spread over varying targets, time frames and cost centres in the statutory and voluntary/community sectors
- - the need to develop creative thinking about shared budgets with the recognition that preventative work saves money on crisis intervention
- - dependence on dedicated project staff who act as conduits for information and frequently have a role as catalysts for change. The question then arises as to how this information will be shared if and when those individuals are not there
- - 'targeted' services focused on working in a particular neighbourhood can be reluctant to engage with initiatives that operate across local authorities.

In addition, there are some specific challenges for parents, which arise from joint working across services and professions. From disabled parents' point of view, having their family life discussed and information shared more readily between agencies can be threatening. The issue of

confidentiality remains a concern, particularly where it remains unclear to a parent who is sharing information with whom and what the consequences might be. From this perspective, joint assessments across children's and adults' services may be evidence of joined-up thinking by professionals, but in fact may sound alarm bells for parents. While professionals tend to have a positive view of the potential of multi-agency working, from a parent's point of view involving more professionals may be problematic. It is important not to overlook these concerns. There is clearly a need for more information on what can be done to make sure that the benefits of multi-agency working experienced by professionals are also shared by parents.

As well as the broad issues raised by multi-agency working, we now consider issues that have arisen in the context of specific inter-agency relationships.

10.3 Working across adults' and children's services

'We've had a lot of stuff to get over, historical stuff, to get where we are now ...'

Adult social worker working with the Community Team for Parents with Learning Disabilities in Stockport

In the process of developing a shared positive ethos, agencies often find that historical mistrust and conflicts surface and need to be dealt with. There have often been difficult relationships between adults' and children's services in relation to working with families. The two sets of professionals work to different legislation, with different roles and responsibilities. Specialist adults' services may feel concerned that children's services will be too quick to make judgements about parenting capacity without first assessing a parent's support needs. Children's services may be worried that child protection concerns are not taken seriously enough. Initially, therefore, working together can heighten differences that have not been faced in the same way before.

The specialist learning disability social worker who is part of the Stockport team illustrated both the difficulties and the benefits of working across existing boundaries between adults' and children's services. She explained how initial questioning and mistrust of one another's roles had gradually been replaced by an increased understanding of one

another's contribution, to the point where children's services increasingly view the project as a useful resource. The team introduced a parenting course based on the work of Webster-Stratton and they feel that this has helped to persuade children's services that they understand about children's, as well as adults', needs.

Where necessary, the Community Team for Parents with Learning Disabilities in Stockport has made referrals to children's services. Children's social workers have come to appreciate that the team will take a strong stance on child protection where it is called for. By the same token, the team's input at child protection meetings is respected because of their knowledge of families.

'Quite often they [children's services] will ask us now about parenting capacity and we will complete that section [of the assessment].'

Community nurse, Stockport Community Team for Parents with Learning Disabilities

The benefits of increased understanding are felt across both adults' and children's services. The Stockport team now takes referrals that at one time they may have refused because children's services were involved. The adult social worker on the team said: 'We've even said [to children's services] ring us ... and we'll come and do an assessment. If parents don't meet our criteria then perhaps we can refer to you.' This cooperation is making it easier to link parents with specialist adults' services and arrange support in the voluntary and community sectors.

As well as heightening differences of approach, working together makes it easier to see where there are gaps. For example, the team at Option 2 suggested that at the more intensive level of mental health difficulties and drugs and/or alcohol-related problems, there has been a tendency among children's services to think solely in terms of child protection and to overlook parent support. Meanwhile, specialist adults' services have the competence to support adults but, because their role is often limited to the needs of individuals, have tended to ignore the family context. In consequence, the issue of parents' support has historically been overlooked by both sets of professionals.

Cooperation and mutual understanding across adults' and children's services in Greenwich has been assisted by the presence of a liaison worker who has encouraged joint working on a number of fronts, including

organising ‘duty swaps’ between the referral and assessment service (who are the front-line team for children’s services) and the home treatment teams (who are the front-line assessment teams from the community adult mental health service). This has been mutually instructive and has given each a better understanding of the other’s roles.

Joint service protocols that have been produced in Greenwich encourage workers to carry out joint assessments where appropriate. Different timescales and different types of assessment in adult mental health and children’s services have taken adjustment on both sides, although workers say that they are learning more about how to do this. The representative from children’s services present at the Greenwich meeting expressed the hope that the new role of lead professional, part of the *Every child matters* framework, will help with the liaison.

The liaison worker in Greenwich attends community mental health team referral meetings and feels that an important part of her role is explaining to adult mental health services what children and families’ services do and how their procedures work. There is now much closer liaison between adult mental health workers and children’s social workers when there are safeguarding concerns. In addition, children and families’ workers are increasingly likely to be involved in ward-round meetings where discharge of an adult patient is being considered and there are children at home.

The liaison worker has deliberately made herself as visible as she can, repeatedly asking questions and also distributing laminated flow charts she has produced, one of which shows how services should link together and others which deal with particular aspects of collaboration.

In addition, documents have been produced with the involvement of the CAPE project which address the following specific interface issues:

- - referral across midwifery services and community mental health teams
- - referral for mothers with mental health problems on the labour ward or post-delivery
- - referral within the children and families’ division of social services
- - inter-agency protocol for a psychiatric inpatient who has children
- - pre-birth assessment and referral protocol.

A shorter leaflet sets out information for parents with mental health problems about how to access support services.

It was generally agreed at the meeting in Greenwich that there has been a real shift over the time that the liaison worker has been in post, as people learn about each other's roles and start to ask the right questions – 'Does this adult have children?', or alternatively, 'Does this child have a parent with a mental health problem who needs support?'. The hope is that all of this is contributing to an organisational culture change so that these things begin to happen automatically and routinely, whether CAPE project workers are present or not.

The CAPE project also identified a need for more creative thinking about budgets in relation to prevention and joined-up working, especially where children are not in immediate need. This issue is discussed further in Chapter 6.

Social workers at the Cheshire meeting reported that they often perform joint assessments when working with disabled parents. They described these as an informal hybrid of community care assessment and assessment using the *Framework for the assessment of children in need and their families*. Where possible they carry out both assessments at the same time so that parents do not have to repeat themselves. Sometimes one social worker will conduct the assessment and report back as appropriate, with social workers from both agencies deciding on how the funding will be divided. The plan is that this process should continue to operate when adults' and children's services separate in the course of 2006.

Senior managers from adults' and children's services have worked together from the outset in preparing the *Norfolk protocol for enabling parents with a disability or long-term illness* and this is felt to have helped greatly in the preparation of the protocol. A senior manager from children's services commented that both adults' and children's services found that working together helped them to understand how different legislative perspectives, policy directives, timescales, vocabularies and working priorities fit together.

This learning can now be more widely shared by the manager seconded to oversee the implementation of the protocol in Norfolk as it is rolled out more widely within adults' and children's services. The children's services manager also mentioned a 'steep learning curve' that faced children's services as they took on board the extent to which parents can feel alienated and confused by a specialist use of terms and language

that strikes parents as alien and on occasion stigmatising. Her comments were reinforced by the parents present.

For their part, adults' services valued the opportunity to look at spending, assessment and other inter-service issues across adults' and children's services. It was proving particularly timely to have established dialogue about how the two services might work together more closely, as, since the initiative began, the decision has been taken to move adults' and children's services apart structurally.

Adults' and children's service directors have each committed to the implementation of the protocol ahead of the restructuring process and managers feel that this will help in making the necessary links across the new structures. The secondment of a manager to roll out the policy and protocol across the two services and to help 'link in' with other services and agencies seems particularly crucial in this context. It was vital that the role should be extended for a sufficient length of time to ensure effective implementation.

The Norfolk protocol identifies the need for services to work together in the context of young people who have been identified as 'young carers'. Effective cooperation was seen as essential to ensure that the appropriate service response is delivered in good time to prevent avoidable problems from developing or to address problems that have arisen already.

'The needs of all carers, including young carers, should be recognised. Time-consuming and/or inappropriate tasks and responsibilities which adversely impact on a young person's physical, emotional, educational or social development should be avoided by providing adequate and acceptable support services to the disabled/ill parent and their family.³⁶⁹ (See Appendix.)

Where a parent's care needs and/or parenting-related support needs must be addressed so that their child/ren does not continue to be burdened by excessive or inappropriate tasks, this would be the responsibility of adults' services. Where what is required is, for example, counselling for the young person or supportive peer contact with other young people, children's services or the youth service would have a responsibility to make sure that this was being addressed. There might be a number of areas, such as liaison with schools or leisure opportunities for families, where adults' and children's services would share responsibility for making sure that the need was met.

The intention of Norfolk's *Protocol for Enabling parents with a disability or long-term illness* is that adults' services should work together with services directed at 'young carers' so that timely and effective support is provided by the appropriate service to meet the needs of each member of the family and to avoid reinforcing the concern expressed by some parents that where they have additional support needs their children will be regarded as unpaid carers.

10.4 Coordination with maternity services

In Stockport, the midwifery service's experience of supporting a couple with learning difficulties was an important impetus for setting up the original inter-agency steering group. The couple's new baby had been removed from the home, and adoption proceedings were started against the parents' wishes without any consultation with the midwife who had been working with them. With the support of local advocacy services, the midwife supported the parents to contest the court order. The child is now with its parents and the Community Team for Parents with Learning Disabilities are continuing to make sure that these parents are adequately supported.

Partly as a result of this case, the midwifery service has from the outset been central to the development of the inter-agency 'pathway' in Stockport, with the particular involvement of the consultant midwife. Midwives in Stockport have a resource pack about the needs of parents with learning difficulties and about procedures to refer mothers and fathers to a specialist support service from their earliest point of contact. The Community Team for Parents with Learning Disabilities support women to attend antenatal appointments and do their best to ensure that the information parents receive is accessible and clearly understood. They work in partnership with other health professionals and statutory services to undertake pre-birth assessments. This may involve practical support in the home and training on specific areas such as preparation for the baby's arrival, budgeting and healthy eating.

Support is at its most effective if it can begin within the first half of pregnancy. Ideally, the team would like to work with prospective parents at an even earlier stage. One social worker referred a couple who were thinking about having a child to the team for family planning advice. In this instance, alongside basic sex education and information about

parenting, the team liaised with the housing service because the couple were living separately in sheltered housing at the time.

The head of midwifery in Greenwich explained how mental health had, for a long while, remained something of a gap within the weekly multi-disciplinary meetings at the maternity hospital, which involve midwives, health visitors and representatives from children and family services. There was a place on the form that each pregnant mother filled in asking about mental health. The head of midwifery pointed out that it is not just a question of ticking the right boxes but also of following through with appropriate action. Having duly filled the forms in, the midwifery service never received any feedback from mental health services and in consequence ‘... never quite knew how to close the loop’.

The liaison worker attached to the CAPE mental health project now attends the meetings held by the maternity service and is also involved in training the midwives. The head of midwifery also talked about increased awareness as a result of the Climbié inquiry. The midwifery service, she said, had started to think much more about the issue of neglect: ‘There were loads of people involved and yet still we got it wrong ... A midwife’s role, right at the starting point, is crucial ... Right at the outset of record-keeping, early in pregnancy, mental health needs should be noted and responded to’.

The midwifery service in Greenwich has, together with the liaison worker, developed antenatal protocols. They have a clinic for pregnant women with drug and/or alcohol related problems and are starting another for mothers with mental health problems.

10.5 Coordination with health

One of the strengths of multi-agency working is that gaps and shortcomings in services become readily apparent and can then be specifically targeted. By the same token, multi-agency working can help to highlight difficulties that parents are having in accessing mainstream health services. For example, the Stockport team became aware of a gap in support for parents with learning difficulties after their contact with the maternity services has come to an end and before their children start school. This made the team conscious of a need to foster closer links with health visitors, as the front-line professionals whose job it is to work with parents of pre-school children.

Using money from the Children's Fund and in conjunction with Mencap, the Community Team for Parents with Learning Disabilities plans to run a training course for health visitors to promote knowledge and understanding of the needs of parents with learning difficulties.

Adults' social services in Cheshire reported that in the past it has been difficult for health and social services to work out how best to cooperate. As work is undertaken to bring adult health and social services into a closer organisational relationship, managers consider that improving services to disabled parents could be one of the beneficiaries. In particular, the plan to create one Cheshire primary care trust whose boundaries are coterminous with social services should create opportunities for health and social services to develop integrated support to meet the ongoing primary care, specialist and acute health care needs of disabled parents and their family members.

The creation of a joint target around health and community well-being, adopted jointly by health and social services in Cheshire, presents an opportunity for both the local authority and the primary care trust to set specific goals in relation to working across social services and health to support disabled parents.

The parents present at the meeting in Cheshire endorsed the need for greater liaison between health and social services and expressed the hope that specific gaps between the two services in relation to disabled parents' support needs could be addressed.

The issue of liaison across health and social services was particularly important to parents who have other disabled family members and find themselves spanning a number of administrative categories across different services. The tendency to divide things into distinct and separate services may be designed to make administration easier, but parents described it as making family life 'nightmarishly complicated' at times.

A grandmother who has a sporadic physical condition supports her daughter, who has learning difficulties, with parenting. One of the major difficulties is that, with fluctuating health needs, support needs can change dramatically from day to day. The family found that the situation was significantly improved when they started to receive direct payments and had far more control over how support was delivered.

A younger mother with a physical impairment has a daughter with mild learning difficulties. The support needs for their conditions fluctuate from day to day. 'As a parent, your anxiety about your child's bad

day and your bad day coinciding only adds to the stress.’ This mother also experienced difficulties when she was trying to plan ahead, knowing that she had to go into hospital for an operation. She was told to come back if there was a problem. When she came out of hospital it took eight weeks for health and social services to put help in place. It seemed to her that there was no coordination or forward planning between the two services.

In Norfolk a parent cited a hospital pre-admission clinic that fostered good links with social services as an example of good practice. Good liaison of this nature is crucial for parents and professionals alike because of the potential impact on children’s welfare.

10.6 Coordination between the statutory, voluntary and community sectors

Voluntary and community sector involvement, mentioned in the course of the project meetings, ranged from pre-school provision to the use of a local vegetable box scheme for underprivileged families. The range of joint working, in many cases involving both statutory and non-statutory agencies, was also broad. It included:

- - meeting targeted training needs (in Stockport)
- - a research and development initiative spearheaded by disabled parents (in Cheshire)
- - providing lower levels of support for families who do not reach eligibility thresholds for statutory services or who have received services but need ongoing support (in Greenwich and Stockport).

In Norfolk all the work in the children’s sector (including statutory, voluntary and community initiatives) is being logged electronically as part of the process of preparing the authority’s children’s plan. The children’s services manager highlighted that specialist adults’ services geared to supporting parents would need to be consciously included in this mapping exercise.

In both Norfolk and Cheshire it was felt that the exhaustive mapping of voluntary/community sector children’s services is not sufficiently mirrored in adults’ services. In both places it was stressed that voluntary/community organisations need as much knowledge as possible about

work in all sectors to make appropriate referrals and make the fullest possible use of resources.

Organisations working with different groups of parents may not know about each other, nor do they necessarily know who best to link with in social services. An adults' social worker in Cheshire said that a parent who approaches a local voluntary organisation for support might, on occasion, find themselves being referred to children's services, where adults' services would have been more appropriate.

Voluntary/community sector services tend to be less threatening to parents, who, although sometimes very positive about individual social workers, are frequently wary of social services as a whole. In Greenwich, for example, it was recognised that parents might find it less threatening to approach the Family Welfare Association for support than social services.

Statutory services in Stockport identified that following a crisis intervention there will often be an ongoing need for good support among parents with learning difficulties. It is often both more appropriate and more cost-effective to refer parents to voluntary and community-based services.

It was felt by project managers at the CAPE project in Greenwich that the Family Welfare Association's Building Bridges project is likely to have a role in continuing to work with families referred to the CAPE team by social services once immediate and serious concerns are past and what is required is ongoing low-level support to make it less likely that problems will recur.

Where organisations are found with the right training and experience to deliver ongoing, post-intervention support to parents this is highly valued by statutory services and parents alike. However, the relationship between the statutory and non-statutory sectors is not without its problems. Service providers in the statutory sector become wary of the voluntary sector and community-based organisations if problems arise with consistency of support or there has been a lack of appropriate training. Those organisations with a particular brief to support adults may not have received training in child protection issues, while organisations centred on children's needs may be unaware of the difficulties that parents are having in accessing support. Few agencies are geared to working both with children and adults.

The convener of the disabled parents' reference group in Norfolk thought it important not to overlook the strong links that many disabled parents themselves have with the voluntary sector. In addition to being present as individuals, several of the parents at the meeting in Norfolk also represented other groups including the Disabled Parents Network, CHANGE, LearnDirect, Deaf Connections and Guide Dogs for the Blind. Other parents on the group represented a parent befriending service and a phone advice line funded by the health service. The involvement of parents may on occasion help to unlock voluntary sector funding (for example, in relation to training) that would not otherwise be available.

Local groups of parents also have the potential to exert influence as part of local policy groups. The convener of the parents' group in Cheshire pointed out that she serves on the local maternity services liaison committee and attempts to keep the issue of disabled parents on the agenda there. The convener of the Norfolk parents' group considered that there might, as yet, be untapped potential for disabled parents to influence emerging policy directions in local areas.

Sharing information

In this chapter we discuss messages about making information accessible to disabled parents, explore what makes services good from parents' and children's points of view and highlight the role of parents themselves in service development.

11.1 Adapting information and making classes accessible

One area in which liaison between the statutory and non-statutory sectors appears to have been particularly fruitful is in the adaptation of information to meet the needs of disabled parents and in making parenting classes accessible.

A health care coordinator, employed by South Norfolk Primary Care Trust and with a specialist brief to work with parents with learning difficulties, has put in place a number of supports for parents. Initiatives include the establishment, in collaboration with Sure Start in Thetford, of a parent support class aimed at parents with learning difficulties. The group was set up at the request of parents and gave them the information and support they asked for. The parents explained, for example, how the image of dealing with each egg in the box in turn had been used as a visual image to show them a way of coping calmly with problems one at a time.

As noted earlier in this practice survey, the Stockport community team worked together with the local adult education service to adapt a cookery and child nutrition course. The course avoided written evaluation and as much information as possible was communicated through pictures and symbols. Where parents needed to write things down, they were supported to do so.

If working with an expectant parent or couple, the Community Team for Parents with Learning Disabilities in Stockport use specific, targeted materials such as the manual for parents with babies and young children devised by CHANGE (which the parents group in Stockport themselves

helped to develop). They also adapt information to make sure that it is well suited for the learning styles of the parents that they are working with. For example, the team has adapted a Webster-Stratton parenting course, presenting information in pictures and symbols as much as possible, and developing an audio cassette to accompany the course.

Parents who have used the service in Stockport are considering writing an information leaflet for other parents. Meanwhile, the team has developed a simple written leaflet to put in GPs' surgeries, antenatal clinics, and so on, that is aimed at both parents and professionals.

In the consultation meeting held with parents with drug and/or alcohol related problems, one mother spoke of the value of taking part in a parenting class. Others had felt inhibited about attending classes with other parents for fear of being 'shown up'. Several of the parents (both mothers and fathers) had found TV programmes such as *Super Nanny* and *Little Angels* to be helpful. Two parents who had completed college courses had found that this had helped to build their self-confidence, which in turn helped them as parents.

Before looking at what the practice survey tells us about what makes good practice sustainable and what might help to embed developments within local authority practice, we consider what makes services good from parents' point of view. These messages are key to understanding good practice given the importance of positive engagement with parents in overcoming anxieties about seeking help from statutory services.

11.2 What makes services good from parents' point of view?

In discussions, parents said that they would like the following supports to be available:

- - access to mainstream family services (such as antenatal clinics) and information in accessible formats
- - easy access to new mainstream support services such as those provided as part of the Sure Start initiative and their children's schools
- - information and parenting education, adapted where necessary to individual requirements and provided in time to meet particular information needs

- - support to fulfil parental responsibilities such as getting children to school, speaking with teachers, helping with homework, and getting children to health appointments
- - where required, support to enable parents to take their children to school or to leisure activities themselves, rather than relying on someone else to do this
- - transport and housing where these are essential to enabling them to look after their children
- - mainstream and specialist parent supports for all parents who need it, including fathers and parents who work
- - opportunities to make their own contribution, for example by helping out at their children's schools.

Access to information is a particularly important issue and parents identified the following needs:

- - Sex education should be available and accessible to disabled children and children with learning disabilities.
- - Mainstream services and websites should include and be accessible to disabled parents so that they do not feel that they are being forced to rely on specialist health or social services.
- - Parenting classes should be accessible to all parents. This means designing classes that are accessible for Deaf parents who use British Sign Language and others for whom English is not their first language, parents with learning disabilities, fathers, etc.
- - It is important for teachers to be imaginative about sending information home from school (for example, putting information on tape rather than sending notes to someone who cannot read or who is visually impaired).
- - Parents appreciate professionals who show imagination about adapting resources, for example, pictures showing how to bathe a baby.
- - Disabled parents need accessible information about what services are available and how to access them.

Parents identified the following as characteristics of good services:

- - supports that are in place before problems arise

- - services that are responsive to changes in individual and family situations
- - good information about how service providers can help disabled parents
- - information explained clearly in everyday words, particularly since some words or labels sometimes have a different meaning when used by professionals than they do in normal conversation
- - being kept well informed about what is going on (it should be made clear why a professional has come to the home or is seeking a meeting with a parent, what will be done with any notes, what the parent is allowed to read and how they can find someone to act as an advocate if they feel they need one).

Parents said that they do not want:

- - to feel that they are constantly falling between administrative categories: adults'/children's; social/health; mainstream/specialist; adults' and children's disability services (when disabled parents have disabled children)
- - to feel that they are being shunted around by service providers trying to avoid meeting costs
- - to have to take on stigmatising or unwelcome labels just to access resources
- - the needs of parents with invisible impairments and/or undiagnosed conditions to go unmet.

A group of children who have disabled parents were consulted as part of this knowledge review (see Appendix 1). They expressed views on the ways in which they felt that support should be delivered to their families:

- - Support should enable children to have good times with their parents, not just good times with other adults.
- - Sending children on outings or holidays without their parents can be helpful at times but there is also a need for families to do enjoyable and educational things together.

- - Support should strengthen disabled people in carrying out their role as parents independently.
- - People who come to assist a disabled parent should help in the way that the family asks them to, not in the way they think they should.

Disabled parents highlighted that it is important that disabled people should be facilitated to make their contribution as adoptive parents, kinship carers and parent mentors. Experienced parents who have succeeded in raising children (sometimes against professional expectations) can be a really valuable resource for other parents, for example supporting other parents to ask for an explanation of terms used by professionals that they do not understand.

Many grandparents are involved in supporting their adult children with parenting and/or take a major role in looking after grandchildren. Parents felt that the needs of disabled grandparents or disabled kinship carers should be assessed routinely as part of their own community care assessment, as well as being taken into account in children's assessments.

It should not be more difficult to persuade the authorities that a person is fit to foster or adopt purely because they are disabled. Nor should it be assumed that disabled people will primarily be interested in adopting or fostering disabled children – this may or may not be the case.

Parents from black and minority ethnic groups who took part in the consultation reported that in spite of their right to receive a culturally appropriate service, as stated in the Children Act 1989 and the Disability Discrimination Act 1995, they did not feel that their expressed needs and preferences had always been taken into account and that practitioners' judgements were on occasion affected by cultural assumptions. Examples given by parents included the amount of time that it might take to shop for and prepare specialist foods and the amount of time needed for dressing children's hair in particular styles.

11.3 Involving parents in service development

Earlier work underscored that the involvement of disabled parents often has a qualitative impact upon service development.³⁷⁰ Across the projects there were examples of parents being involved in a variety of ways and at various stages of the process including identifying difficulties in

accessing services, helping to develop protocols, feedback and evaluation of ongoing service delivery, and participation in training.

11.4 Practicalities of involving disabled parents, including those who are currently service users and those whose views are seldom heard

Parents from the Norfolk reference group made the point that, as well as hearing from experienced, confident parents and parent representatives, it is important to get feedback from parents who are currently service users on what it is like to use services, what works well, what would help to make support more accessible, and so on. It was felt to be particularly important to consult with parents whose views are seldom heard about why they find it hard to use services and/or those whom services find hard to reach (for example parents from ethnic minorities, parents with learning difficulties, fathers, gay and lesbian parents and parents with substance-use related problems). These parents are potentially experiencing the greatest barriers to participation and therefore local authorities who are serious about consultation will need to be creative in finding ways to engage their involvement.

In Stockport, parents with learning difficulties at first attended the steering group meetings but reported that they did not feel comfortable about participating. It was also difficult for some of them to attend meetings regularly because of things going on in their own lives. A solution was found by using an advocacy support worker to report back to parents on the steering group's meetings and communicate parents' views to the steering group.

Reflecting with clients on the impact of the support they have received is built into the work of the Community Team for Parents with Learning Disabilities in Stockport. Feedback from parents is discussed at regular review meetings which are held for the sole purpose of examining the work that is being done and how it is perceived and taken up by parents. At the Option 2 project in Cardiff, most of the families and social workers fill in an evaluation form. Parents' views are included in the Annual Report and are used to evaluate and refine the model.

The key role that parents can play in stimulating, informing and sustaining commitment to service development was reflected in the comment of an adult social worker in Cheshire, 'Sometimes there is a greater

sense of commitment when something has emerged from the grassroots at local level'. However, parents were also concerned that consultation should not just be 'an exercise in checking the user participation box'. Parents expressed the need to know that their contribution will genuinely make a difference. Parents who attended the meetings in Norfolk and Cheshire pointed out that a number of practical issues need to be addressed if parents are to be fully involved in developing and evaluating services. These included the following:

- - Time restraints may be particularly complex for disabled parents, for example, they may need to be available to collect children from school, need additional time to rest and so on. Parents may need to use crèches or to cover the cost of substitute child care.
- - Additional transport costs and the practical difficulties of arranging accessible transport need to be taken into account.
- - Information associated with consultation, participation and evaluation needs to be available in accessible formats and in straightforward language.
- - Jargon needs to be avoided, technical terms explained and meetings conducted in a way that makes it possible for parents to participate fully. Some parents may need facilitators.
- - Parents need feedback (in accessible formats) about the input they have made and what is going to be done with it.
- - Venues need to be accessible and comfortable for parents. This is particularly important when involving parents who may feel quite uncomfortable if asked to venture into what they see as 'social services territory' to attend a meeting. Voluntary sector premises are often preferable.
- - Some parents are reluctant or unable to attend meetings far from home.
- - Sometimes parents do not feel comfortable meeting with officials, or in groups, and would prefer to feed back their comments to an advocacy worker or in a one-to-one situation.

The consultation carried out as part of this knowledge review with parents who have drug and/or alcohol-related problems was held at a Sure Start project with a crèche attached. The parents who attended the group

commented that they appreciated being able to meet in a mainstream, non-stigmatising context.

A shared commitment

In this final chapter we explore the issue of what makes good practice sustainable, looking in particular at training, evaluation and the need for creativity in sharing the costs of support. We also touch on an area that will require further exploration if good practice is to become more widespread, that is, the relationship between local and national drivers in developing supportive services for the parents covered by this knowledge review.

12.1 Training

‘Joint training across the statutory and voluntary sectors will be of key importance in developing effective services to disabled parents.’

Cheshire Social Services’ recommendations from a meeting of managers to discuss the development of services to disabled parents, 19 October 2005

Training was identified in each of the good practice examples as an essential part of embedding and sustaining good practice. It was felt that when key people leave or when staff from other agencies who have been involved in liaison move on valuable progress can ‘soak away into the sand’ unless the people who replace them are informed and trained to work in the same way. Senior managers in Norfolk expressed the view that to sustain good practice it was necessary that the organisational culture subscribed to the philosophy that underpins it. Training was expected to play a vital role in this.

In Norfolk, training has, from the outset, been fundamental to the success of the implementation plan. Pockets of good practice are evident but it was felt that there was insufficient consistency across the county. It is considered that the protocol will not be effective unless it is accompanied by training aimed at changing the attitudes and behaviour of social workers in both adults’ and children’s services. Training should also involve the range of agencies to improve understanding of different ways of working, different use of language, different timescales and so on.

Senior managers pointed out that there will not be a lot of new money to direct towards implementation of the protocol and that achieving a 'cultural shift' through training will therefore be essential to establishing new ways of working.

It is not yet clear exactly how inter-agency training will be funded in Norfolk and it is felt that part of the necessary cultural shift will be for each of the different services and agencies to recognise that they will need to make an ongoing commitment to training at every level and across every agency. It may be that social services will have to start the ball rolling or it may be a question of pooling funds. If training leads to changes in attitude and behaviour this would lead to decisive improvements in services without huge expenditure. A senior manager in adults' services said, 'It's about making the most effective use of the money that is available'.

It was pointed out by the liaison manager in Norfolk that staff at all levels of agency provision – from initial contact services through to senior managers – need training to enable them to respond appropriately when approached by disabled parents. Since not all parents choose to use direct payments it is also important to provide training for staff who work for care agencies or in-house services. There are many issues to be covered, including understanding of their role in supporting disabled adults to parent, health and safety issues, and attitudes towards disability, impairment and illness.

Workers supporting parents with learning difficulties in Stockport highlighted the value of training certain professional groups to plug gaps that have become evident during the course of inter-agency working. Training in this targeted way may be directed at exploring a particular issue across a range of professional groups and agencies or it may include particular groups that have identified a need to learn more about each other's way of working. (See the example given in Chapter 10 of the way in which the Community Team for Parents with Learning Disabilities provided training directed at health visitors.)

12.2 Involving parents in training

In Cheshire, a senior manager from adults' social services expressed the value of parents' contribution to training: 'There is no substitute for hearing real people telling it like it is'. The point was made that

while not all parents will ‘want to perform live’, their experiences can be written down or videoed for use in training. It can be very useful to have feedback from parents on what is going well and what they are finding helpful, as well as identifying places where service providers are getting it wrong.

In Stockport, parents with learning difficulties have made videos to help train professionals. Parents with learning difficulties in both Norfolk and Stockport have worked with CHANGE, a national organisation of parents with learning difficulties, to raise awareness of difficulties that they face in finding support with parenting.

The parents’ group convener in Norfolk pointed out that, while parents will be able to speak from experience and will have an extremely valuable contribution to make to training, this should not mean that they are expected to make this contribution without appropriate remuneration, skills training and resources. From its inception, the Norfolk parents’ reference group has been thinking about the best way of developing parents’ role as trainers both locally and further afield. The convener of the parents’ reference group considers that parents will have an information and training role throughout the county and that parents require training to build up the expertise they will need for the task.

12.3 Monitoring and evaluation

At the outset of this knowledge review, the stakeholder group made the point that new initiatives (in many cases pioneered within the voluntary sector) are often short-term and not well placed to carry out proper evaluation of outcomes over a period of time. The lessons to be learnt from potentially valuable service interventions are therefore sometimes lost. This view was echoed across the good practice examples with a further point being made that even ongoing local authority services may be difficult to evaluate because costs and benefits are spread over several different cost centres. A further, and in some ways even more fundamental, difficulty is the fact that the benefits arising from preventative initiatives are difficult to quantify either financially or in terms of the social benefit to families.

Evaluation was viewed both as a potential driver – providing useful information on which to base future decisions – but also as a potential brake. For example, external demands to meet nationally imposed targets

can result in a narrow focus aimed at boosting statistical data in a certain field. Currently, the emphasis is described as being 'on the "heavy end" of child protection work', so that the demand for data has tended to be in that area, while the outcomes of preventative interventions may not be adequately reflected in short-term statistical analysis.

Pressures to produce measurable results were felt by some practitioners to be deflecting attention away from a range of preventative interventions vital to the long-term welfare of families. It can be extremely hard to measure the impact of such services precisely because they are aimed at prevention and have an impact on medium- to long-term outcomes that may be difficult to observe.

Nevertheless, the importance of using evaluation to develop knowledge-based services was widely recognised within the good practice examples. The Option 2 project regularly reviews its practice, particularly in the light of feedback from parents. Internal evaluation is ongoing and is reported in the service's annual report. Families involved in the project have typically maintained positive progress in relation to their goals throughout the year following the intervention, and the project has been successful in preventing children from being removed from home over the three-year period in which families have been monitored.

The need for external evaluation is regarded as a matter of priority by Option 2 workers. The project team hope to find funding that will make it possible to validate independently the effects of the project's short-term crisis intervention work with families in terms of family cohesion and longer-term outcomes for family members.

The CAPE project just beginning in Greenwich plans to build in evaluation mechanisms. The intention is to explore what might be the most appropriate methodologies after an evaluator has been appointed. The project has been gathering a list of names of parents willing to be part of consultative focus groups reflecting local needs and issues. These groups and other evaluative measures will be put in place as early as possible in the life of the project, although the project manager pointed out that, ideally, evaluation would have begun alongside the appointment of a liaison worker two years ago, as that was the point from which practices and attitudes began to change. Increasing the access that agencies have to one another is a considerable gain of the work that has taken place so far, but managers expressed the view that it might be hard to assess the effects of this retrospectively in terms of outcomes for families.

Workers involved in the CAPE project spoke of the value of collecting qualitative data about families' and professionals' perceptions of how well services are working and monitoring how this changes over the course of the project. It is an altogether more challenging task to collect quantitative data that can be used to show the effectiveness of interventions.

The project has prioritised the need to work with an evaluator to develop research procedures that can be used to examine changing patterns of accommodating children and indices of parental and child well-being alongside case study material and evaluative feedback from families and service providers.

The project manager expressed the view that if it were possible to demonstrate that an intervention had resulted in saving money on the number of placements of children in care, this would help to secure funding. However, health and social services professionals remain uncertain about the feasibility of evaluating the effects of service intervention. For example, the children's social services manager present at the meeting in Greenwich pointed out that, in some instances, the involvement of the project might actually mean that a child had been taken into care sooner. In any case, he said, how do you demonstrate whether you have prevented a child from going into care or not? How do you demonstrate that a family unit is more viable in the long term than it was before the service was provided?

12.3.1 Evaluating cost effectiveness

Managers from social services in Norfolk agreed that it is notoriously difficult to calculate how cost effective a particular service or initiative is when it comes to interventions and services aimed at prevention. The benefits may not be clear cut or immediate, even though the work done may make a real difference in terms of family outcomes. In other areas of work such calculations were considered to be frequently more straightforward. For example, in Norfolk it has been possible to demonstrate the extent of the savings that resulted from the introduction of direct payments and to deploy some of the money saved for training. But it was almost impossible to calculate cost savings in terms of work to support parents because the benefits to families are so much harder to quantify. It was felt that this was likely to be an even greater problem

at times when budget pressures focus senior managers' attention on very immediate issues in relation to budget viability.

Weighing up the cost-effectiveness of different interventions was illustrated at Option 2 in Cardiff where it was pointed out that the annual cost of running the project is only slightly more than the cost of keeping one child in residential care for a year. Between them the two therapists, supported by a shared administrator, work with roughly 12 families a year. Given that these families' children were in imminent danger of being removed from home, the project team felt that it would not be hard to demonstrate the cost-effectiveness of Option 2.

In a northern city authority that has adopted the Option 2 model developed in Wales, senior managers have employed the concept of 'deficit funding' (projecting potential savings and diverting the money to pay for a preventative intervention) to establish the service.

The complexity of making valid comparisons and fiscal trade-offs in relation to work that covers different legislative requirements and service priorities, spans unconnected budgets and operates over a variety of timescales was raised as a problematical consideration. In Norfolk, there is a clear understanding that, if current initiatives are to be maintained and further developed, politicians and senior managers will want to see evidence that expenditure has positive outcomes. While it is possible to monitor expenditure on parenting support across children's and adults' services, managers expressed the view that it is harder to match this expenditure against outcomes for the parents and their children. It would be even harder to assess whether expenditure on supporting parents reduces pressure across all the services that a family may use, including health and education, and across the statutory and non-statutory sectors.

In the first instance, therefore, the decision has been taken that whenever a referral involving parent support is made to either adults' or children's services it will be logged in both services. Expenditure on parent support will also be logged across the two services. This should provide a basis for collating evidence about expenditure on support for parents in relation to referred needs and hopefully will go some way towards providing actual figures on what is spent on parent support across the two services. Factual papers will then be prepared to take to the relevant review panels of local councillors. At that point, an informed

decision can be made about whether it would make sense to operate some kind of joint budget.

12.4 Local and national performance targets

‘There is a challenge to develop local performance indicators which can track activity, service quality, and outcomes across organisational divides, so that we maintain an awareness of how disabled parents are assisted.’

Roy Taylor, Director of Community Services for the Royal Borough of Kingston upon Thames and a non-attending member of the stakeholder group, in an email to the authors, December 2005

A range of opinions was expressed on the value of national performance indicators versus the value of determining priorities at local level.

In Cheshire it was agreed that services to disabled parents might be linked into an existing local initiative around health and community well-being, which involves both health and social services and that this would be a useful way of tapping into local funding to develop this area of work. At the same time, a social worker with responsibility for developing the use of direct payments felt that a national performance indicator in this area would provide a useful signal to local authorities about its importance.

Conversely, a Norfolk county councillor expressed the view that not having a national performance indicator gives greater freedom to local authorities to respond to unmet needs that have been identified locally. The manager of adults’ services agreed that a problem with national performance indicators is the need to try and balance what has been identified as a national target with decision-makers’ perceptions of what needs doing locally. However, the manager from children’s services expressed the view that the spending balance within children’s services between family support and child protection may not be completely right and that a national performance indicator signalling a shift towards family support could be helpful.

To summarise, it was felt that national directives indicating the importance of developing support to disabled parents, combined with the setting of specific local targets reflecting local priorities and conditions,

would serve to highlight the importance of the issue and prove effective in directing a maximum of resources to the process of developing and sustaining support.

12.5 Budgets and funding

Since there are no national incentives in relation to disabled parents, professionals felt that it would be important for local authorities to be proactive in finding suitable local and national funding streams to foster the development of better services. It was felt that careful consideration would be needed about the best way to keep the issue of support for parents with particular requirements on local authority agendas. This will be a particular challenge in authorities where there are already serious concerns about overspending. Both in Cheshire and Norfolk senior managers were clear that while the work that is to be done has the backing of directors and is firmly on the agenda, no new local authority money is likely to be made available. Senior managers in both places pointed out that this would make it necessary to find ways to progress the development of services within existing funding streams.

It was also suggested that small pockets of money from social services or from the non-statutory sector will need to be found to progress specific tasks as and when necessary. Possible local funding streams were discussed, for example the children's social services manager in Norfolk suggested that some of the money set aside for their teenage pregnancy strategy could provide sex education and parenting education for young disabled adults. Creating the capacity to continue resourcing developments is essential to embedding good practice.

12.5.1 Creating joint budgets: a possible strategy

In Norfolk, as in other places where children's and adults' services are separating, it is recognised that although the restructuring will increase inter-agency cooperation between agencies working with children directly, it may make cooperation more difficult between adults' and children's services in supporting disabled parents.

As explained above, one of the central aims of those responsible for implementing the Norfolk protocol is to make operation and cost sharing between adults' and children's services more straightforward than it has

been. Up until now there has not been a clear procedure for sharing the funding of support for disabled parents. This may suggest the need for the creation of joint funding under appropriate leadership. The provision of services to adults may well lead to positive outcomes for children and it is considered reasonable for children's services to put more money in. Senior managers who are promoting the protocol are pleased that the two directors have agreed to monitor spending on parent support across their budgets. Although there are no immediate plans to create a joint budget, this will at least provide a basis for making an informed decision.

12.5.2 Financial sustainability

Representatives from several of the projects expressed concern about the long-term financial viability of the work developed or proposed. Financial concerns that threaten to dominate the service agenda in Norfolk and Cheshire have already been discussed above. The resources for work at Option 2 in Wales, the CAPE project in Greenwich and the work done by the Community Team for Parents with Learning Disabilities in Stockport are a mixture of local authority involvement, voluntary sector funding and money from government initiatives such as Supporting People and Neighbourhood Renewal.

This kind of mixed economy is an increasingly common basis for funding crisis intervention and intensive levels of support for families identified as belonging to 'disadvantaged' and 'minority' groups. This has the advantage of providing scope for innovation. However, it was felt that such arrangements are also accompanied by a degree of anxiety as project personnel are forced to spend time and energy on securing ongoing funding. It was also argued that funding 'one-off' projects is not a good basis for embedding good practice routinely in local authority service responses to parents with additional support needs. Evaluation of work funded out of particular budgets such as spending on drug and/or alcohol reduction strategies, or support aimed at people with learning difficulties or adults with mental health problems may remain poorly disseminated and insufficiently linked with statutory support structures, unless senior managers take an interest and definite steps to make sure that this happens. This can mean that worthwhile initiatives remain insecure while, at the same time, the broader potential of learning from them remains undeveloped.

In Norfolk, in Greenwich and at the Option 2 project in Cardiff there are intentions to monitor expenditure against outcomes. In each case it is hoped that the results of such evaluations will help in finding a more sustainable basis for supporting the work currently being developed in the longer term.

12.6 Service leader commitment

Good practice often has its origins in the commitment of proactive individuals or small specialist teams, in the voluntary sector or among parents themselves. However, the commitment of directors and heads of service, across both adults' and children's services, appears to have had a key role in helping to embed good practice in local authority structures. On the basis of this good practice survey we would say that arrangements for making sure that disabled parents' requirements are routinely and consistently addressed in time to prevent unnecessary problems from arising are still at a very early stage of development. These services seem to have the best chance of continuing to develop and become established where there is an explicit commitment from heads of services. In relation to both crisis interventions and routine ongoing support, provision is described, even by those currently involved in its development, as patchy across England, Wales and Northern Ireland and at the same time insufficiently monitored and financially insecure.

Representatives felt that clear drivers are needed to encourage service leaders and political decision-makers at local levels to develop services for parents with additional support needs. This is necessary to ensure that support is routinely delivered with appropriate specialist involvement in time to prevent avoidable difficulties from arising. At the same time, incentives are required to encourage front-line workers to work outside their immediate parameters to develop new ways of working with these parents, and in liaison with other agencies.

12.7 Conclusions

This is a good juncture to reflect on the premise of this knowledge review: that it is a valid exercise to consider the term 'disabled parents' in the broadest sense, as including parents who may have additional requirements related to physical and/or sensory impairments, learning difficulties,

mental health, drug and/or alcohol misuse-related difficulties and those with serious illnesses, including HIV/AIDS. Naturally, this inclusive approach presents challenges in terms of what it has been possible to achieve within the limits of this review, and also for local authorities in considering implications for their own practice. In some ways it is more straightforward to develop separate services aimed at distinct needs. Indeed, giving attention to developing specialist service responses and resources specific to the needs of particular client groups and the demands of particular situations is clearly essential. At the same time as reinforcing the importance of appropriately informed and directed parent support, this survey of good practice suggests that developing an overarching conception of inclusive parent support is both an achievable and useful thing to do.

Neither family life nor disability are static entities, and the literature review reminds us just how complex the interplay between the two can be at times. Dividing service provision into relatively impermeable compartments that are hard to move between can, as the parents consulted throughout this knowledge review told us, be a source of great frustration. The consequence can be services that do not adequately address the vicissitudes and complexities of family life and disability.

It is important to recognise that across the range of experiences covered within this knowledge review, parents face common issues around the extent to which their support needs are addressed, the extent to which the necessary links are being made across service divisions and the extent to which services are approachable and accessible. There is evidence that the groups of parents covered by this knowledge review, however different their individual experiences, report a common fear of approaching social services for support. Whether or not individual anxieties are justified is not the point, since merely the fact that parents are anxious about approaching social services for support may act as a barrier to parents seeking help. Unapproachability is a systemic problem, which professionals recognised and wanted to address. Involving a range of parents in the development of services and working together with the voluntary sector, which many parents find easier to approach for help than statutory services, are both regarded as important to success.

The good practice examples provide evidence that developing flexible and non-stigmatising forms of support to parents and families is something that is being achieved across the range of impairments and

health-related situations covered in this knowledge review and across the spectrum of family need. This strengthens the argument that an inclusive approach to parent support is achievable.

The core issue is not delineating the distinctions and overlaps between groups so much as establishing whether local authorities have flexible systems and appropriate resources in place to make specialist and mainstream supports available. This is in line with the responsibilities placed upon local authorities by legislation and guidance as outlined in the literature review that forms the first part of this knowledge review.

In order to set up parent support strategies that are truly inclusive it is necessary to recognise that services aimed at prevention will be required across a variety of different levels of need and in a range of family circumstances.

- - preventing unnecessary problems from arising by addressing specialist parent support needs for information, equipment and assistance
- - anticipating and where possible preventing family crises, which could lead to children being accommodated
- - supporting parents where children have been removed from home, with a view to reuniting families where possible
- - post-crisis support aimed at anticipating and preventing future difficulties.

Preventing poor outcomes for children by providing appropriate specialist support to parents will involve different ways of working in different contexts. Significantly, in each of the good practice examples we have looked at the concept and practice of prevention remains on the agenda throughout the work taking place with families.

The *Every child matters* agenda, with its potential positives of bringing services and agencies working with children closer together, may at the same time prove counterproductive for disabled parents if local authorities and the voluntary sector do not develop effective ways of working across adults' and children's services. Where existing gaps in services to disabled parents remain unaddressed, the current restructuring within services to children and services to adults has the potential to extend those gaps. The good practice examples demonstrated that an active commitment is needed on the part of service leaders to develop the necessary links between adults' and children's health and social services, schools,

parent education, family support, crisis intervention services and housing, and across statutory and voluntary sectors.

Challenging though it might be to establish joint working the examples of the good inter-agency working that we saw suggest that finding ways to work together across professional boundaries has proved extremely rewarding and that professionals feel better able to support disabled parents effectively. However, the good practice survey suggests that the benefits of multi-agency working have yet to be perceived by parents themselves. Given the importance of creating services that are acceptable to and welcoming of disabled parents, attention is needed to making sure that the way in which agencies work together is more transparent and more evidently supportive of disabled parents.

No matter how good the work that is emerging is, those involved are very aware that it can thrive over the longer term only if it is in a position to withstand changes in personnel, fluctuations in budgets, structural reorganisation and shifts in priorities. Local authorities need to be informed by robust evaluation of outcomes across the relevant agencies and service divisions so that the development of good practice can be knowledge based and backed by a programme of ongoing training involving staff at all levels. For effective support for disabled parents to become established, practice needs to be embedded in service structures and backed by flexible financial structures and monitoring arrangements and it must have the capacity to evaluate outcomes across agencies and service divisions. For these things to be possible, the commitment of service leaders and local politicians will be needed so that work can be integrated into local work programmes and strategies and be backed by appropriate resources. This in turn will call for clear policy drivers and practical incentives from central government about the importance of addressing the support needs of parents with additional requirements.

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Appendix

Consultation groups

Consultation was carried out with five of the groups that are currently under-represented in the research literature on disabled parents and those with additional support needs. This appendix describes why we picked the particular groups, how they were recruited and how the discussions were organised.

SCIE paid the costs of venue, catering and travel expenses and fees to those participating and also paid administration costs incurred by the organisations that helped with setting up the meetings. Notes from each meeting were distributed to participants following the meeting, and comments and amendments invited.

Children of disabled parents

In general, research on children of disabled parents has concerned young people receiving services as young carers. We therefore sought the views of young people whose parents are disabled but who have not been identified as young carers. The Disabled Parents Network, a nationwide organisation of disabled parents, was asked to convene a group of children of disabled parents. There were five children (three boys and two girls) present at the meeting, aged from 8 to 14. One or both of each young person's parents were users of social services because of a physical impairment.

The young people were asked to comment on occasions when having someone to help their parent had worked well and other times when it had not worked so well. This was followed by role-play exercises which gave them the opportunity to explore a range of family situations, commenting on what they felt would be good ways of meeting the needs of all family members. A more personal discussion arose out of this, in which young people discussed the ways in which external supports can be most helpful to families and also talked about the value of peer support.

Parents with drug and alcohol-related problems

Most of the consultations involving families affected by parental substance abuse have been with children, spouses or other relatives. It was felt that it was also important to hear from the parents themselves. The group was convened by a project that offers counselling support both to parents with drug and/or alcohol-related problems and to other family members where requested, including children.

The discussion group met in a room at a Sure Start project where there were also crèche facilities. The group was attended by three mothers and two fathers, all of whom were receiving individual counselling from the project. In addition the two men have attended a short-term father's group and two of the women have attended a short-term mother's group run by the project.

The group was presented with a summary of the main findings of research in relation to parents with drug and/or alcohol problems. In discussion, parents commented on the research findings and talked about what were useful characteristics of support from the point of view of themselves and their families. There was also an extensive discussion on the value of peer support in the context of parenting.

Parents with HIV/AIDS

There is very little in the research literature about the experiences of parents with HIV/AIDS. The organisation Positive Parents and Children, which runs a support group for parents and leisure activities for children in South London, helped us to consult with this group. The funding provided by the knowledge review enabled us to meet with this group one Saturday afternoon at a local community centre. Parents and children had lunch together and then the workers from the project took the children to the cinema while the parents participated in a discussion.

Seven parents participated. A summary of the research literature was provided in advance and parents were asked to comment. They were also asked about their experiences of services – good and bad. The discussion was wide ranging, but particularly important issues were the side effects of medication, the need for help with looking after children, and the value of services provided by organisations such as Positive Parents and Children.

Black and minority ethnic disabled parents

The experiences of black and minority ethnic disabled parents are under-represented in the research literature. Equalities, the national council of disabled people, carers and people with long-term impairments from black and minority communities, helped us to consult with black and minority ethnic disabled parents. They invited parents to a meeting at their offices in North London. Six parents attended, who had a variety of experiences of physical and/or sensory impairments and/or long-term health conditions. They also had children of varying ages. Advocates from Equalities also participated in the meeting.

Participants described some very distressing experiences concerning the impact of poverty, poor housing, impairment and illness. Experiences of services had been almost entirely negative and parents' accounts graphically illustrated the value of advocacy services.

Grandparents

The experiences and views of extended family members where a parent is disabled and/or has additional support needs are under-represented in the research literature. There is some evidence that the involvement of grandparents may be crucial in terms of children's well-being and there is increasing attention being paid to 'friends and family care/kinship care'. However, little attention has been paid to the role that a grandparent may have in supporting his/her adult child in their parenting role.

Grandparents Plus organised a meeting. Seven people attended (including one couple) who had adult children with learning disabilities or mental health problems and all were involved in some way or another with looking after their grandchildren. Issues raised included the difficulties that they experienced in helping their adult children get the support they need, financial difficulties which arise from supporting both adult children and grandchildren, and the difficulty grandparents experience in getting children's social services to recognise their role and support needs.

Supporting disabled parents and parents with additional support needs

This knowledge review is about parents with physical and/or sensory impairments, learning difficulties, mental health problems, long-term illnesses such as HIV/AIDS, and drug or alcohol problems. Its main focus is on social care, but integral to this are the relationships between social care and health, housing and education.

The knowledge review looks at social care in both the statutory and non-statutory sectors. It pulls together a comprehensive review of the literature, and reports on a diverse range of good practice, that draws upon the experiences of disabled parents. It is predominantly concerned with how policies and practice address the needs of parents, and progress in overcoming barriers. While the needs, experiences and rights of children are important, they are not the central focus of this literature review.

This publication is available in an alternative format upon request.