



research in practice

Parental mental health problems:
messages from research, policy and practice
by Jo Tunnard



Very few children think their parents
are completely sane. They're right:
we're all potty half the time.

Children are mystified by their parents' behaviour. They have to cope, and they want to do so. They have a deep sense of allegiance. We need to open our eyes to how wide-eyed are the children who are watching us. The more severe the parent's illness, the more perplexing it is for the child. But we can do a lot to help parents.

Peter Wilson, Director of Young Minds, opening a conference
on the impact of parental mental health problems, September 2003

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Published 2004
ISBN 0-9542562-4-7

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about this research review

One of the main ambitions of **research in practice** is to make it easier for those who deliver services to children and families – be they working in local authorities, local or national voluntary organisations, health settings or national government organisations – to access reliable research, distilled and translated with their particular needs in mind. This series of research reviews covers key practice areas identified by practitioners, and key research strategy issues identified by planners and policy makers. The work and methods of **research in practice** chime well with the developing national agenda to build more effective, multi-professional and multi-agency services for children, in part by creating and using reliable research evidence.

The topic for this research review emerged from discussions with practitioners and their managers over a number of years. While there is often a good deal of research information available on the impact on the person with a particular problem – as there is indeed in the case of mental health problems – there is often little on the impact of the problem on those who live close to it. And yet this is the very area in which social care workers are charged with making life-changing assessments. An additional concern, and one that has become more acute in the increasing separation of adult and children’s social services within local authorities and elsewhere, is the gap between providers of services to adults and children. This causes frustration to workers and often misery to the families involved. We hope this review will help bridge that gap and be useful for all those working with families where a parent has mental health problems.

QUALITY MARK This review has been peer-reviewed by a range of academics based in universities and service agencies, and by practitioners and others seeking to assist the development of evidence-informed practice. We are grateful to them all for their generosity and good advice. What follows here has benefited enormously from their wisdom: Jo Aldridge, Lin Bell, Liz Brown, Lindsey Calpin, Fiona Colquhoun, Elizabeth Cooke, Hilary Corrick, Gabrielle Crockatt, Marie Diggins, Dave Ellis, Janet Gadsby, Liz Garnett, Sarah Gorin, Nick Gould, Carol Joughin, Bill Joyce, Lisa Keay, Sal Lodge, Deborah Loeb, Tony Newman, John Randall, Mary Ryan, Paul Stallard, Michele Wates, Sarah Webb and Clare Whately.

Special thanks are due to Sarah Gorin and Tony Newman for their generous advice in addition to their peer review and to Cathy Humphries for her helpful contributions about domestic violence.

Celia Atherton
Director of **research in practice**

For Mike, Mel and Lou
in memory of our parents

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introduction

This review – like previous ones in the series – focuses on one particular aspect of parenting and family life. It is about children living in families where a parent has mental health problems.

The review highlights that:

- Mental health problems are very common: it is likely that we, or someone close to us, will be affected during our lifetime.
- Adults with mental health problems are among the most excluded groups in society.
- Moderate to severe mental health problems affect an estimated 1.7 million adults and 2.5 million children in the UK.
- Parental mental health problems can have negative consequences for families, in particular on relationships and child development, and especially where problems are severe and complex and parents and children are unsupported.
- The compelling links between poverty, mental ill-health, discrimination and social exclusion make it important that responses are based on a broad understanding of family and neighbourhood circumstances.
- Local projects demonstrate what it is possible to achieve for parents and their children, especially where services build on parents' strengths and their aspirations for their children, and where mental health problems are neither obscured nor allowed to dominate unduly.
- Few approaches in the UK have been evaluated robustly.
- Despite recurring pleas from all quarters, it remains hard to bridge the gap between mental health work with adults and child care work with children and families.

The aim of this review is to identify – from a range of publications – sources and messages that might help practitioners and managers improve their understanding of the circumstances of children and families living with parental mental health problems, and find responses that have the potential for achieving positive change.

The review is intended for social care practitioners, and for managers with strategic, operational and training responsibilities for the delivery of family support services. Those with local responsibility for implementing the vision behind the proposed Children Act 2004 (Gr*) – especially in relation to joint assessment, information sharing and early attention to family difficulties – may find useful material for the development of new models of working. We hope the review will be of particular interest to those striving to create greater links between adult mental health services and children and family services, so that responses to the needs of different family members are underpinned by a shared professional understanding and a commitment to joint work.

* For an explanation of this referencing system, see p14

This is not a new aspiration. As Göpfert and colleagues, writing almost a decade ago about child and family mental health interventions, commented:

thinking about children and parents is often kept artificially separate because services are organised to deal with individuals and not families. (F1, first edition).

In the new, second, edition the authors acknowledge the progress that is being made in different countries. But they point, too, to the continuing tensions and competition that make it difficult for professionals to provide family-sensitive services, despite the growing awareness that ‘keeping family in mind’ has benefits for everyone, because:

it helps parents recover, protects the welfare of children, and enhances the quality of life for the family unit’. (F1, second edition)

definitions and approach

For the purpose of the review, the term ‘parents with mental health problems’ is used to denote parents who are experiencing such emotional distress that they find it hard to function as well as they would wish, and they and/or others are concerned about the actual or likely impact this is having on their children. Parents may or may not have a formal diagnosis from a GP or specialist mental health service, and they may or may not be in contact with statutory or voluntary agencies.

This working definition links with government initiatives and priorities. The Emerging Findings of the National Service Framework for Children (NSF) refers to ‘children whose parents have mental health problems’ and includes them as part of the group of children defined as being ‘in special circumstances’. This means that the children’s circumstances are deemed to merit particular attention, in order to boost the chances of children achieving similar outcomes to their peers (G2).

The NSF for Adult Mental Health (G3) stresses the importance of a continuum of need and services for adults, from mental health promotion for all to in-patient and long-term treatment for those with specific illness and disorders. This internationally recognised continuum includes three broad categories of mental health need:

- 1 the relatively low-cost mental health concerns and needs of the entire population of parents
- 2 the higher-cost, but somewhat less prevalent, issues associated with moderate mental health problems
- 3 the highest-cost, but relatively rare, issues associated with major mental health problems in parents (H1).

In this review we focus on the second two of these categories, the moderate and major mental health problems of parents, rather than on

the everyday worries of those with child care responsibilities. **Moderate problems** include those difficulties that are sometimes now referred to as ‘common’ mental health problems – including depression and anxiety. **Major problems** include those conditions that are generally described as ‘severe and enduring’ – including severe depression, manic-depressive illness, schizophrenia, and dual diagnosis (when two or more problems affect someone at the same time). Throughout the text we use the term ‘parental mental health problems’, except when referring to a specific mental health illness or disorder.

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.

There has been a tendency in the recent literature to deal with a range of parental issues together – especially alcohol and drug misuse, domestic violence and disability. Other material, focusing on mental health problems alone, has tended to deal with family experiences where parents are at the serious end of the spectrum of need and so likely to qualify for specialist adult mental health services.

There is merit in both these approaches. Clearly, the needs of children whose parents have severe and enduring mental health difficulties demand particular attention. In relation to all levels of need, it is common for parents to have co-existing (or co-morbid) difficulties, where two or more problems are experienced at the same time, such as alcohol plus drug misuse or substance misuse plus mental health problems. Children may experience a range of difficulties at home and it can be hard to disentangle the impact of one problem from another. Clustering studies provides a larger pool of information, and that can bring advantages when drawing out lessons for the future - a good example is the summary report of what can be learnt from child protection studies about the impact on children of parental drug misuse, domestic violence and mental illness (F2).

This review adopts a slightly different approach. It covers the spectrum of both moderate and more severe parental mental health problems, but it deals with them as a discrete topic. It does so because there are some particular needs for those children who do live in families where parents have mental health problems.

The children are more likely to need to understand, and then cope with, adult behaviour that is unusual, sometimes bizarre. There is the deep stigma that attaches to mental health problems, and the pervasive fear that children will be separated from their parents if family circumstances become known. There is the extra fear, often unspoken, that children will inherit their parent’s symptoms, and that families and professionals may be powerless to prevent that.

Another reason for identifying issues relating to parental mental health problems alone is that these tend to get overlooked in studies that deal with multiple issues. A particular problem identified by some researchers is the difficulty in gaining access to families who might be willing to take part in research studies (see B5, B6, F14). Some reports attribute this to practitioners being reluctant to make introductions for fear that parents will become unsettled if asked about their circumstances. Other researchers highlight the need to be more creative about ways of making contact with families.

how many families are we talking about?

Current government information about mental health problems suggests that they are as common as asthma, with one in six people of working age in the UK having a problem (most often anxiety or depression) at any one time (G3).

The general population survey in Great Britain (G4) reported on the prevalence of what the researchers categorised as minor (neurotic) and major (psychotic) mental health problems. The distinction is similar to the moderate/major definition referred to earlier (H1). Minor (or moderate) problems included depression and anxiety, and they were experienced in the survey week by almost one in seven of the adult population. They were more likely to be experienced by women.

Major mental health problems included manic depression, schizophrenia and dependence on drugs or alcohol. The prevalence of these was much lower than for minor mental health problems (affecting one in 40) and younger adults and the unemployed had higher rates than others.

Social class was relevant for both minor (moderate) and major problems, with unskilled and manual workers having higher rates than others. The unemployed were twice as susceptible to mental health problems as those in paid work. People living alone or with few close relatives were more prone to symptoms than others.

What were the findings in relation to parents? The presence of any mental health problem – minor or major – was highest among parents (whether alone or in a couple) living with dependent children. There was a higher rate of mental health problems of all types among lone parents: they were three times more likely than other parents to have a major problem, and almost twice as likely to have a minor problem.

Smaller-scale studies add to our knowledge. A quarter of adults referred for in-patient hospital psychiatric treatment are likely to have dependent children (E1). A quarter of women diagnosed with schizophrenia live with children under 16 (E2). Between a third and a half of children in touch with ‘young carer’* projects are helping to care for a parent with mental health problems (B3, F3).

* A term generally understood to mean children who are carrying out excessive or inappropriate roles within their family, usually on account of the disability or ill-health of one or both parents. There are, of course, many children living in similar circumstances and not providing care for their parent or parents.

Local audits of need round off the picture. They 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. Such audits also point to the overlap between mental health and other problems, as for instance in the latest Children in Need Census in one English authority which showed that, in cases where domestic violence was an issue, parental mental illness was more than twice as likely to feature than in other cases (E3).

Particular caution is needed when trying to use local data to gauge the national picture. What can be said with confidence is that available figures are more likely than not to underestimate the true position of both child and parental needs, since studies consistently show that the mental health system has not addressed the parenting role of psychiatric clients. Information on their children is not collected routinely, and the specialist needs of their children are seldom identified or referred by adult mental health workers to specialist children's services.

The conclusion to be drawn is that there are many children living in families where at least one parent has mental health problems. Lone parents are especially vulnerable, and women are more vulnerable than men, whether alone or with a partner. Many parents with mental health problems will be managing their difficulties and raising their children, often with limited community supports.

It is hard to be precise about how many. The National Service Frameworks, both the Emerging Findings for children (G2) and the final version for adult mental health (G3), are silent on the point, except that the latter refers to the World Health Organisation's prediction of a sharp increase globally in severe mental illness by the year 2020. Earlier work by Falkov (J1) has estimated current prevalence in the UK: just under four per cent of all parents with dependent children have mental health problems, using the term in the sense of the moderate to severe problems on which this review focuses. Extrapolating figures, this amounts to approximately 1.7 million adults and 2.5 million children.

the policy context

The context for parental mental health work has been marked by changes in emphasis that have both influenced, and been influenced by, shifts in policy, procedure and practice in mental health and related fields. Recent government initiatives provide optimism that developments might accelerate in the near future – in particular, joint work between adult and children's services might be boosted by such initiatives as the named children's lead at the Department of Health, the post of Minister for Children, Young People and Families based at the Department for Education and Skills, and the legal and policy

changes expected from the Green Paper *Every Child Matters*, the proposed Children Act 2004 (G1), and the National Service Frameworks (G2, G3). In relation to adult mental health needs, there is to be a cross-government team and an independent advisory group to help implement and monitor progress on early support for families (G5).

On the other hand, there is the risk that the development of Children's Trusts and other local re-structuring of children and family services – also envisaged in the new legislation – may have the unintended consequence of making joint work between adult and children's services more difficult to achieve because structures are likely to become more, rather than less, rigid as a consequence. There is, too, the simultaneous and sobering message from government, of the lack of significant change in the pervasive stigma and discrimination against people with mental health problems (G5).

During the past two decades a key feature of the policy context relating to parents with moderate or major mental health problems is that parents have come to spend more time with their families, including their dependent children. In part, this is because improvements in medication mean that more people are able to manage their symptoms out of hospital. At the same time, policies to move people out of long-stay institutions have prompted the growth of mental health care in local neighbourhoods, alongside the more general move towards community care for adults, with families providing a person's main care and support needs and public services providing additional support.

In child care, parallel policies have stressed the importance of children growing up in their own family or, if that is not possible, of retaining links with parents and other relatives. As a consequence, there has been an increase in the number of children who spend some, much or all of their early years in families where at least one parent has mental health problems.

Running alongside these developments, the role of parenting has been the subject of tensions and debate, with particular focus on two separate but related issues – the role of the adult patient and the role of children living with them. It has been a source of great frustration to parents with mental health problems and other disabilities that local authorities have been slow to include their parenting needs when assessing eligibility for community care services. Their frustration has been compounded at times by developments in 'young carer' services, especially where attention is focused exclusively or predominantly on the children, to compensate for the adverse impact of their assuming responsibility for excessive or inappropriate care tasks at home. A critique of the history of the 'young carer' movement is as relevant to mental health needs as to other problems faced by parents (F3).

This debate has been one example of the divide between those who want to reach out to the children, as potential children in need, and

those who take the view that if services addressed the needs of the adults the children could get on with their lives much better. The trend at present leans towards tackling the root of the problem, by promoting the rights of disabled parents to receive support with their parenting role and by viewing this approach as key to the welfare of their children (F4).

The organisational gulf between adult mental health services and children and family services also creates tension. The split tends to leave one group of practitioners focusing on the needs of adults as individuals with mental health problems, with little attention to their needs as parents, while the other group of practitioners focuses on the needs of children, with little experience of how to address the mental health needs of parents. The structural divisions are reinforced by professional training and traditions as well as by competition for limited resources. An additional problem is the high eligibility threshold that applies to each service.

A further piece in the jigsaw is the negativity that attaches to mental health problems. As researchers have commented, the focus of law and policy has been about protecting society from mentally ill people and protecting mentally ill people from themselves (A4). The media has shaped attitudes and perceptions, linking psychotic illness in particular with danger to the public. Research has, until recent years, placed heavy reliance on measuring and recording negative outcomes of parental mental illness. In the past, and still today (H2), the quickest way to obtain support for a family has been as a consequence of the risks posed or the need to protect children, and child care social work has also had a negative image. All this has served to reproduce and reinforce negative stereotypes, of both mental health difficulties and the families affected by them.

There have been considerable attempts, especially in the last decade, to shift these attitudes, through practice guidance, policy statements, and training and public education initiatives. In the mid-1990s carers became entitled to have their own needs assessed and included in their ill relative's care plan, and Department of Health guidance accompanying this change argued against children caring beyond an appropriate level. In 1999, the government's National Strategy for Carers (G6) urged professionals to work with the family as a whole rather than continuing to work exclusively with the adult being cared for. In 2002, the Fair Access to Care Services guidance (G16) specified that social roles – including parenting – should be considered as part of a disabled person's assessment.

These developments built on the Care Programme Approach to mental health needs that had been introduced in 1991 (and updated in 1999) to provide a new structure of assessment, review and key working for those with severe and enduring mental health problems (G7). Subsequent Community Care Guidance has stressed the

importance of remembering that families do their best; that the ability to parent can be limited by poverty and by disabling environments, services and attitudes; and that assessments should start with the family's needs, and service plans should start with the family's solutions (G8). Another development has been the extension of assessment and services – for young people with care responsibilities at home – through the Carers and Disabled Children Act 2000.

There has also been a growing move within government to shift the focus of health policy. There is the Women's Mental Health Strategy (G9), launched by the Department of Health in 2002, although this has rather little to say about women's specific needs around parenting. The development of the NSF for adults has identified mental health as one of the two earliest priorities for development, including both mental health promotion and mental health treatment. Emerging findings in relation to the NSF for children highlight the importance of services to boost family stability for those in special circumstances, a category that includes the children of parents with mental health problems.

Progress has been made in children and family social care, too. The Children Act 1989 provides, generally, for the possibility of services for disabled parents in order to enable them to continue caring for children at home. More specifically, it now provides for disabled parents to buy services under the Act, using direct payments granted to them under the Health and Social Care Act 2001 (F4). The Framework for the Assessment of Children in Need and their Families (G10) is beginning to be used more widely across agencies, boosted by the government's drive for greater clarity in assessment and information sharing. The renewed aspiration for providing services at an early stage, before problems have become entrenched, is also welcome (G1), as is the emphasis on focusing less on problems and focusing more on boosting the resilience factors in children's lives (F1, first edition).

A key influence on the developments mentioned above has been the contribution of family members to the debate. In particular, the Disabled Parents Network has been instrumental in encouraging government to take a critical look at the parenting support offered to disabled adults (including those with mental health, drug and alcohol problems), and to make recommendations for improved practice (G11). Disabled parents have also taken part in the Joseph Rowntree Task Force on parenting (H3), established to improve support services to disabled parents. They have influenced, too, the work of the Social Care Institute for Excellence (SCIE) which is amalgamating examples of best practice in relation to inter-agency collaboration in services for disabled parents (H4).

Work on mental health policy and legislation has been accompanied by other initiatives. The Department of Health spends a million pounds each year co-ordinating a campaign to promote the message that mental illness is neither shameful nor uncommon (J9).

Government funding has also been allocated to training materials, notably the early Crossing Bridges pack (J1) which is intended to improve cross-agency understanding and responses to parents with mental health problems and their children. Alongside the training pack, several local projects were funded to test new ways of working. Both strands of work were a direct response to the consistent findings in research studies that families needing help were poorly served by – in part at least – the inability of adult mental health services and child welfare services to adopt a joint approach to family needs.

There are challenges ahead. The experiences of black parents and their children highlight the failure to meet whole family needs, and to do so in ways that are culturally appropriate and non-stigmatising. The main thrust of government adult mental health policy and service development focuses on severe mental illness rather than the ‘common mental health needs’ experienced by so many more parents. More attention is needed to these lower-level problems that can and do leave parents struggling against the odds.

how the review was conducted

The intention was to focus on UK research conducted in the last decade. However, it became clear from preliminary searches that current research relies heavily on older material and so the scope was extended in order to include this earlier work. Other European work published in English, and some studies from North America and Australia have also been included, because they offer useful insights and ideas for practice.

Policy and discussion documents and other, non-research, papers have also been scrutinised, either because they were mentioned in research studies or because their subject matter is relevant to the review. With both the research and other material the intention has been to draw on the views of those with expertise in the subject matter, notably family members (children, parents and other relatives) and professionals (those in practice and those involved in policy development and implementation).

Searches – using various terms to signify parental mental health problems – were conducted on the library databases of the National Children’s Bureau (NCB) and the National Society for the Protection of Children against Cruelty (NSPCC), followed by searches of more specialist databases (including MEDLINE and PsychLit) and use of both the Royal College of Psychiatrists and the British Library. Colleagues in research and practice proved to be another valuable source of information, for their challenging questions about what should be covered and their suggestions about leads to explore, ranging from local projects to internet websites.

This was not a systematic review of the research evidence about parental mental health problems. If that had been the aim, studies of

potential interest to readers, because of their useful insights into attitudes or experiences, would have been excluded because of weakness in their methodology. Nor was the review to be a comprehensive mapping exercise of current programmes. As such, there will inevitably be gaps – both about research in progress and about local developments. The starting point has been to draw on work from various quarters that highlights key messages for practitioners and commissioners working in adult and children’s services.

In contrast to earlier topics in the series, especially parental alcohol misuse (F5) and parental substance misuse (F6), there is a wealth of research and policy material available about parental mental health problems – for instance, in the Department of Health summary report from child protection studies there are twice as many references about mental illness as about any other parental problem (F2). There is considerable evidence, too, about the experiences and perceptions of children and – albeit to a lesser degree – of parents and other adult relatives. Studies also provide detailed information about the views and experiences of practitioners (A4, A8).

But there are very few studies – and hardly any from the UK – that seek to measure in a robust way the change that different service responses make to children and families’ lives. In other words, there is a focus on process (what happens), rather than outcome (what changes). The outcome studies that have been found date largely from the mid-1990s, probably because of the policy change in research funding at that time in the USA. This marked a shift away from scrutiny of the genetic influences in parental mental illness towards trying to improve the evidence base for what might alleviate the impact of mental health problems whatever their cause – nature, nurture, social or environmental stress or, indeed, service failure.

As stated earlier, the purpose of this review is to provide information deemed likely to be helpful to those in practice. The main studies included are described in some detail at the end of the review (page 64), so that readers can be clear about both the evidence relied on and the evaluation methods used, and can decide which particular texts might merit closer scrutiny. We have aimed to provide similar information about each study, but this has not always been possible, so gaps remain. And information is, of course, open to different interpretations. It is important for readers to approach research – and reviews like this one – with an enquiring mind.

The 35 main studies cluster in the following way:

A1-A10 impact studies - specific

Ten UK impact studies with a specific focus on parental mental health problems.

B1-B12 impact studies - general

Twelve UK impact studies that cover a range of family circumstances, including – but not exclusively about - parental mental health problems. They are mainly studies of the experiences of children with caring responsibilities at home.

C1-C7 intervention studies - UK

Seven UK intervention studies that describe a service – and its outcome – for children and families affected by parental mental health problems.

D1-D6 intervention studies – other countries

Six intervention studies from other countries, which, like the studies in group C above, describe a service response to children and family needs arising from parental mental health problems.

Additional references and other materials relied on have been organised as follows at the end of the review:

E other reports of single studies

F literature and research reviews or overviews

G government law, policy and guidance

H local practice experience

J training and other resources.

All these references are listed both in these categories, and alphabetically, at the end of the review.

the impact on the lives of children and families

key findings

This section describes some key findings from research about the main dimensions of the life of children and families – their living situation, their family and social relationships, and their behaviour, health, education and employment. At the start of each sub-section we make a link to relevant aspects of the Assessment Framework for Children in Need and their Families (G10). We do so because child care practitioners welcomed this approach in an earlier review in the series (F6), and because it may be helpful for those working in adult services, especially in light of the growing use of the Assessment Framework across agencies, as part of the work around multi-disciplinary information sharing and assessment (G1).

living situation

- Parents with mental health problems are at high risk of living in poverty, and have very low employment rates.
- The isolation of living with mental health problems is compounded by the fear and experiences of stigma and racial discrimination.
- About a third of children with caring responsibilities at home are estimated to have a parent with mental health problems. The children are more likely than other children with care responsibilities to be providing emotional as well as practical support.

family and social relationships

- Parental mental health problems do not necessarily result in poor relationships between parents and children, but relationships between ill and well parents are likely to be strained.
- Parents need to respond to children's emotional stress in a way that acknowledges and understands their feelings, even if the parent's mental health problem and behaviour is the cause of that pain.
- Communication between family members can strengthen children's ability to move on in life, without worrying unduly about their parents' problems.
- It is generally helpful for children to have information about the causes, symptoms and treatments that relate to their parent's particular difficulty. Information needs to be age appropriate and delivered with care.
- Peer friendships and other informal supports are important for adults and children.

behaviour

- Most parents with mental health problems do not pose a physical risk to their children.
- Children's safety has been more at risk where mental health problems have been psychotic in nature and have co-existed with other mental health difficulties or those arising from social deprivation.
- Parents with mental health problems may be less available emotionally to their children, but other adult relatives and friends can help reduce the negative consequences.
- Children are likely to be better adjusted if they can find ways of accepting or adapting to the stress of living with a parent with mental health problems.

health – physical and mental

- Children with parents with mental health problems are at increased risk of developing mental health problems themselves, through one or more factors – genetic predisposition, the impact of parenting style and ability, and learnt behaviour.
- The emotional stress of having a parent with mental health problems can be great, as can be the fear of the unknown or the fear that children will be removed from their parents.
- There has been a consistent plea for more attention to the prevention and treatment of the health needs of the children of parents with mental health problems.

education and employment

- Studies indicate an increased risk of cognitive impairment in the young children of depressed mothers, but social class and gender are also seen as important, with boys from poorer families more at risk than others.
- The role of schools in providing support to families with mental health problems is less well developed in the UK than in mainland Europe. Parents and children worry about poor responses and negative attitudes.
- Paid work outside the home can be a protective factor against depression, but is generally not available for parents with mental health problems.

living situation

The Assessment Framework provides a conceptual map of key dimensions to consider when assessing children's developmental needs, parenting capacity and family and environmental factors (G10). The dimensions most relevant to this section include income, family history and functioning, community resources, basic care, housing, stability, and self-care skills.

income

A common thread in the UK literature is the link between parental health problems and family poverty. While 50 per cent of all disabled people are estimated to live on incomes below half the national average, that figure rises to 60 per cent for disabled adults with children - the term disabled including those with mental health problems (G12). Mental health problems also have a stronger effect on employment rates than physical health problems. Overall, disabled parents have an employment rate of 52 per cent, and those with mental health problems have the lowest rate for any of the main groups of disabled people – those described as having 'mental illness, phobias, panic attacks' have the lowest employment rate (10 per cent) and those with 'depression and nerve problems' the next lowest rate (23 per cent).

For families already below the poverty level, benefit entitlement after the onset of disability may boost income considerably, but the general message from current analysis of disability, employment and poverty data is that disabled parents run a high risk of being both out of work, and probably poor, for significant periods of time (G12). In turn, poverty and unemployment are likely to add to the stress and other difficulties associated with both physical and mental health problems. For black families, the likelihood of experiencing poverty is far higher than for white families, and the difficulties are rendered more acute because of low income that is compounded by discrimination and exclusion (F7).

These general findings from disability and income studies are echoed in studies of the experiences of children whose parents have mental health problems. They point to, for instance, the gap in benefits for young people helping to look after a parent (B2), and to the added stress – for children and parents alike – when families cannot afford to pay for the recreation and relaxation opportunities available to others (B1).

Studies of depression in mothers describe the important influence of low income. An early study in the UK (E4) pointed to the lack of employment and the care of three or more children as vulnerability factors which, when interacting with others, were likely to result in depression in the working class women in the study. Over two decades

later, another study of depression in women (E5) found that the lone mothers in the sample were three times more likely to suffer depression than either women with a partner or those with no dependent children. The authors argue that the economic and social disadvantages experienced by the lone parents (low income, lack of work, no access to a car) were key influences on their mental well-being.

USA studies also point to the strong association between unemployment and depression, and between low income and mental health problems (F8). They highlight the significant barriers posed by mental health problems for mothers trying to get employment, as well as the likely adverse consequences of children spending all their pre-school years in poverty. Whilst acknowledging the difficulty of disentangling the effects of poverty on children from the effects of their living with a parent with mental health problems, the studies add weight to the plea for policies that will prevent both economic deprivation and its adverse impact on families.

housing and neighbourhood

Neighbourhoods exert an influence on family life. Studies highlight the negative impact of cramped and unsuitable housing, as well as other local adversities. Unsafe neighbourhoods increase stress and anxiety of families living in poor areas: people fear for the personal safety of their children and themselves, and they fear attacks on their property (J1). In a study of the interaction between mothers and young children, poor housing and disputes with neighbours featured more commonly in the lives of the depressed mothers than other mothers (E6). In a later study, overcrowding and reliance on benefits were also much more likely to be the experience of the depressed (A7, E18).

Two recent studies add to the evidence of the link between neighbourhood poverty and mental ill health. One, a report on social exclusion, draws on data showing that the highest rates of depression, anxiety and phobias are found in deprived neighbourhoods (G5).

The second study (E7) is of a random sample of 2,000 children and parents living in a poor parenting environment (defined as having high material, social and structural disadvantage), plus interviews with 45 parents in the sample. The conclusion drawn is that parents in poor environments are approximately three times more likely to score highly on the Malaise Inventory (a test of tendency to depression) than parents in a normal population. The poorer the area, the lower the household income and the greater the concentration of families with accommodation problems, a parent coping alone with child care responsibilities, and a high Malaise score. Whilst many poor parents were coping well in circumstances of great adversity, one of the groups identified as having a need for priority support with parenting was of those with an enhanced tendency to depression.

For some families, the stigma of mental health and other disabilities is exacerbated by simultaneous oppression. A study of predominantly black families revealed that almost all the families were dealing with multiple stresses. Poor facilities for play and leisure, neighbour disputes, racial harassment – these were seen as more of a burden than the care needed in the home (B1). Studies of Asian families highlight similar concerns, especially of the social isolation that is compounded by stigma and racism. Compared to white children in contact with ‘young carer’ projects, the South Asian children felt less able to talk outside the home about parental mental health problems and thought they would get less help from local services than did the white children (B4). In a study of the sources of mental distress in two electoral wards in north England, key worries included the fear of crime, unemployment, debt, parenting, family relationships, and racism. Asian residents formed two-thirds of the 150 people interviewed, and over half related experiences of the adverse impact of racism on their social life, their willingness to use local services, and their general mental well-being (E12).

family circumstances

Disruption to their children’s normal daily life was described by parents in a recent study (A5) as the most common impact of their mental health problem. A third of the parents referred to this. They spoke of being absent from home – on account of emergency hospital admission – at the end of the school day, of the panic attacks that prevented them from attending meetings with teachers, and of not being able to play with their children during periods of depression. Some of the children’s concerns were also linked to interrupted routines – they worried about having no-one to look after them and about where they would live.

Another aspect of children’s lives that has been considered in research studies is the extent to which children are involved in tasks in the home. This has been the main focus of the literature about ‘young carers’.

Overall, the studies suggest that about a third of ‘young carers’ are living with parents with mental health problems. The children may be involved in domestic tasks, such as cooking and cleaning, and care of younger siblings, as well as helping care for parents. What seems key for the children with parents with mental health problems is that they are likely to be providing parents with emotional as well as practical support, and that this emotional support tends to be the more demanding (B2, B3, B11).

Children’s experiences of caring responsibilities can be positive or negative, and are not usually wholly one or the other. The negatives are about restrictions to their social life and friendships (B9), doing household chores (A10), lacking confidence and being made fun of at

school because of family circumstances (B5, B7), restricted choices as they grow older (B1), being used as interpreters (A10, B9), and not having their input at home acknowledged by professionals (A4, B4). Among the positives are feeling that care is support for a loved relative rather than a chore, that caring is something done for the good of the family as a whole, and that it is an activity done at particular times rather than something that defines the child's life (B1). Studies also describe how parents and children take steps to protect against too heavy a burden. For example, parents speak of involving other relatives and making sure children can contact adults quickly (A9), and children talk of spending time with friends and doing activities away from home (D5).

Closely linked to children's input at home is the extent to which families find themselves coping alone. The lack of appropriate services is a common finding in studies that seek the views of family members (A10, B4, B5, B6, B11).

Up to a third of families in one study were receiving no outside help for a parent's mental health needs, and some of the other families had cancelled services offered to them because they thought them too intrusive or expensive or of poor quality (B3). The poor quality of service was highlighted in another study: the authors report on their alarming finding that home support services (mostly provided by private agencies rather than social services) were generally found by families to be 'ineffective, inflexible, inconsistent, overloaded, lacking in initiative, untrustworthy and occasionally extremely abusive and threatening' (B1).

leaving home

A final point about a family's living situation relates to the timing and reason for leaving home. In relation to young people, those - in one study - who had left home in their late teens had experienced a departure that was either unplanned or not a positive choice (B3). There are two sides to this. Parental mental health problems may prompt some young people to stay at home longer than they wish, because they are needed to help support parents or younger siblings. For others, family difficulties can lead to a premature move, precipitated by a crisis that leaves the young person either unable to cope any longer or wanting a safer place to live.

The other aspect is about mothers and children who leave home because of domestic violence. A study of 58 mothers and children living in a refuge explored the links between children's emotional well-being and family circumstances. It suggested that children were likely to be more resilient if the family environment was generally less conflictual and if their mother was not suffering from moderate to

severe anxiety and depression (E8).

family and social relationships

The Assessment Framework provides a conceptual map of key dimensions to consider when assessing children's developmental needs, parenting capacity and family and environmental factors (G10). The dimensions most relevant to this section include emotional warmth, stability, wider family, family's social integration, and family and social relationships.

It should not be assumed that parental mental health problems are necessarily associated with adverse relationships in families. Indeed, the literature provides considerable evidence to the contrary. It also reveals the different perspectives about relationships that sometimes emerge between parents, children and professionals.

When thinking about family and social relationships, there seem to be five main factors to consider. These are parent/child attachment and relationships, communication, adult conflict, separation and change, and peer friendship and support.

parent/child attachment and relationships

There is a heightened risk of depression for mothers after childbirth, with consistent reports of between 10 and 15 per cent of women being affected. The condition is generally attributed to the physical and psychosocial stress of the birth itself and the new and changed relationships that come in its wake (E6). Studies have long described the impact this can have on mother/baby interactions – mothers may spend less time looking at and touching their baby and respond more slowly to the baby's activity. Where maternal depression – postnatal or otherwise – continues, a significantly lower quality of interaction has been found during the child's second year (E32), and a greater likelihood of insecure attachment in the third year (E9). As with so many other aspects of parental mental health problems, the existence and severity of relationship, social and financial difficulties are deemed to exert an influence.

Parental history may be relevant too. Studies have found a positive association between the quality of attachment between parents and babies and the parents' earlier attachment to their own parents (E10).

The child's temperament may also be an influence. An acknowledged likely consequence of major depression is that mothers may be less sensitive to their children's needs and less responsive to their cues. But some babies are more difficult than others. A study of mothers of babies identified as irritable soon after birth found that mothers could be taught how to respond to their baby's behaviour, with positive results in terms of interactions and attachment (E11). Whilst this study was conducted with well mothers, it may have lessons

for those working with mothers with depression. A similar point, about the importance of providing services soon after birth, is made in a UK review of interventions – such services can prevent infant problems from developing, whilst containing and treating existing parental problems (F9).

For older children, parenting style is deemed important, with impaired relationships more likely to occur where parenting, and discipline in particular, is inconsistent or negative – reflecting the concern about the ‘low warmth/high criticism’ style of parenting that has been identified in child protection studies (F10). Other, specific, situations may raise particular issues, as for instance in refugee-seeking families where parent/child relationships may be put under strain as a consequence of parental mental distress linked to traumatic circumstances before and after leaving their home country (H21).

Finally, what can we learn about relationships from UK studies that report the views of children, parents and professionals? Reports from parents are generally favourable. In the study of children living with a parent with severe mental illness (A4), relationships between parent and children were described as good or strong overall, with improvements during the 18 months after the first study interview commented on in a third of cases. In an earlier study (A5) half the parents said that their mental health problem had changed the nature of their relationship with their child, but this change was seldom described as negative, and several parents described the bond as having grown stronger or closer. The studies suggest that the security of parent/child relationships can be undermined in various ways – by insufficient support for parents, separation, worry that professionals may intervene in unhelpful ways, and by the extra stress of social and financial hardship.

Children’s comments are more variable. In the study just mentioned (A5), when asked what changes they most wanted to see in their family, children said that, first, they wanted their parent to be well and, second, they wanted relationships in the family to improve – this might have been adult relationships, or parent/child relationships, or both. In the other study mentioned above, that of families with parents with severe mental illness (A4), the young people commented favourably on both the care received from their ill parents and the strength of relationships between them – almost all described the relationship as reasonable, good or strong.

In contrast, professionals viewed family relationships as more negative. The researchers comment that these conflicting perspectives may be explained, in part at least, by the difficulty professionals face in making sense of information they receive about the negative

experiences (mentioned by about half the children in the study) in an otherwise positive relationship (A4).

communication in the family

A common finding in research studies is that children of all ages lack information about their parent's mental health problems (see, for example, A5, A10, B1, B3, B4, B9, D1, D5). The omission may be deliberate, prompted by a wish to avoid worrying children. Or it may be unintentional, because those who might be well placed to pass on information lack understanding, or do not know when and how to give explanations. The particular issues children may benefit from understanding are the causes, the symptoms and the treatments that relate to a parent's particular difficulty.

Pioneering work has been done in the USA about family communication, in particular between children of secondary school age and parents who experience severe depression (D4, E13, E14). The work has its roots in the increased risk of depression for adolescents living with a parent with a severe depressive illness – see page 33. The thesis developed was that if children do not understand and articulate what they feel about the effect on them and those around them of parental depression, the confusion that children experience is likely to affect the choices and relationships they make throughout life. They need to communicate what they feel, and so do their parents.

adult conflict

The work of Rutter and colleagues has long influenced professional thinking about the importance of good-quality adult relationships in families. In a paper delivered almost twenty years ago (F11), Rutter summarises the state of research at that time. Key points relevant to this review include the following:

- parental depression is an important risk factor for difficulties in parenting
- the main protective factor with respect to adult depression stems from having an affectionate partner
- family discord that accompanies parental mental disorder is more detrimental for children than the mental health problems themselves, and
- children are most vulnerable when adult hostility and quarrelling directly involve the child in some way.

Later researchers have, almost without exception, set out to build on the classic studies summarised by Rutter. They have also attempted to disentangle cause and effect – do relationship difficulties lead to parental mental health problems, or do mental health problems create the tension between partners?

In a study of the experiences of children living with a parent with severe mental health problems (A4), marital breakdown was seen by

only one parent as the main trigger for the onset of her mental illness. A much more common experience was that relationship problems had both followed the onset of mental health problems and had contributed to the severity of those problems. The difficult relationship had then endured, existing alongside the combination of other family difficulties and the continuing mental health problems.

Where couples (in the same study) had separated, relationships with former partners were described by the women as generally difficult, disruptive or unsupportive. Only one of the 25 lone mothers still in touch with their former partner said he was supportive and understanding about her mental illness. In contrast, half the women with a current partner described him as supportive: sharing tasks, removing children from danger, giving the women confidence.

Relationship difficulties between partners are also highlighted in other studies included in this review, and from different perspectives. In one study (A7, E18) social workers recorded 'marital problems' as the most frequently identified individual primary problem among depressed mothers in contact with social work child care teams. In another study (A8) parents in touch with adult mental health or children and family services mentioned 'partner difficulties' most frequently as a factor that had caused or contributed to their mental health problems. In a third report, a review of three studies with community samples (F12), there were 'robust and highly significant' associations between marital disharmony/conflict and mental health.

The precise nature of conflict and tension between partners is not always defined clearly in research studies. But where there is explicit comment on domestic violence, a link is drawn between that violence and women's mental health problems. In a recent study of mothers with severe mental health problems (A8), high levels of violence and conflictual relationships were described as being 'almost the 'norm' for several of the eleven women in the study, and domestic violence had been experienced by all thirteen mothers in the pilot study. An earlier study, of 116 mothers in contact with children and family social workers (A7, E18), found that the mothers who were clinically depressed were significantly more likely to have experienced domestic violence than the mothers who did not score as being depressed.

The link is made in studies that start from the angle of domestic violence rather than parental mental health problems. In a study of 180 women using the outreach services of Women's Aid Federation (England), there was a strong association between the experience of domestic violence and women's severe emotional distress. Those who had used mental health services had, however, found that domestic violence frequently was not deemed central to their symptoms of emotional distress (A2).

High rates of depression, self harm and symptoms of post-traumatic stress are reported so consistently in research studies that the case is

now argued for a causal relationship between domestic violence and mental distress (F13).

separation and change

Separation and change is another aspect of social and family relationships. First, there are issues about family breakdown. In the small Canadian study of children with parents with moderate or severe depression (D5), five of the six children had parents who were separating or had separated. The actual or feared separation was the single most important issue for the children. Whether the impact was perceived by the children as negative, positive, or a mixture of the two, the separation itself was described by the researchers as ‘a pervasive phenomenon’ in their life. In a small UK study of children of separated parents (E15), three quarters of the parents suffered depression before and after separation and all had received medication for that. Their children were having difficulties, too, but few were receiving help with these emotional and behavioural problems.

Second, there is professional intervention in family life. For some families, the quality of family relationships is affected by the fear that children will be removed from their parents’ care, and the high proportion of care proceedings involving parental mental health problems is well documented (A4, F2, J1).

Physical separation because of a parent’s treatment needs is another area of concern. When parents need inpatient hospital treatment, children’s fears are heightened by their parent’s repeated, and especially unpredictable, admissions, and by the anxiety that the separation may become permanent (A4). Few children in the study had seen their parent in hospital. Visiting was difficult because the hospital setting was considered by parents as unsuitable, or because there were no family facilities, or because children had been distressed during previous visits. The lack of contact left parents, as well as children, worrying about the prospect of long-term separation.

peer friendship and support

Friendships beyond the immediate family, important for both children and adults, may be more difficult to make and sustain when parents have mental health problems. A third of children in one study felt that relationships with peers had changed, and largely for the worse – examples given were of children embarrassed by parental illness, reluctant to bring friends home, becoming more distant from friendship groups (A5). These findings echo reports from earlier studies of the way in which responsibilities at home can curtail children’s opportunities for socialising (B4, B9, B11). At the extreme end are accounts of children being teased or harassed, both for having an ill parent and for helping care for them (A4, B5).

A study of black and Asian families explored this issue in some

depth. Some children did have their choices restricted, but the stronger theme to emerge was that children became selective in what they said to whom and in their choice of friendships and invitations home. They were protective of their family, keeping information private because they knew their peers might not understand their situation. Some were explicit that their difficulties with peers related less to their parents' health problems than to the discriminatory views of others about disability (B1).

Another aspect of peer relationships is that children affected by parental mental health, especially those who have assumed some care of their parent, may have acquired greater maturity than their peers. This attribute is described as having potential as either a positive or negative in a child's life. Early studies, from the 1970s and 1980s, tended to draw more attention than more recent studies to the positives – these include increased morale, the acquisition of new skills, and a sense of fulfilment, provided that the stresses involved are manageable and the tasks rewarding (F11).

There are friendship issues for parents, too. Social networks tend to be compromised by mental health problems as well as other difficulties. Friends (and family) may be deterred from regular and frequent contact by the worry and stress involved in socialising with a person who may be self-absorbed or unpredictable or prone to unusual behaviour. In the study of mothers on social work caseloads (A7, E18), nearly all the depressed mothers experienced isolation and had limited social networks, and for over half of them this was a serious problem. In another study (A4), half of the lone parents had few or no significant relationships with an adult.

Not all is negative, however. Rutter makes the point that it is the quality – not the number – of relationships that counts (F11). In the above study, half of all the mothers reported a good relationship with a non-resident adult family member (A4) and – where available – support from relatives was valued by other mothers (A8). Consultation with service users affirms the value of friendships (E16), and consultation with disabled parents, including those with mental health problems, provides a useful reminder of the importance of local support networks, formed around shared situations and run on peer support lines, sometimes with the input of professionals. Giving, as well as receiving, help is valued.

It is important that all groups of parents, including parents with learning difficulties and those experiencing mental health difficulties, have access to a range of informal and semi-formal supports, as it can make a huge difference to dealing with the issues faced at this stage of parenting – including the often challenging behaviour of small children... Parents not only value being able to find support, but also being in a position to pass on

what they have learned and offer support to others facing similar challenges.
(H5)

behaviour

The Assessment Framework provides a conceptual map of key dimensions to consider when assessing children's developmental needs, parenting capacity and family and environmental factors (G10). The dimensions most relevant to this section include ensuring safety, emotional warmth, guidance and boundaries, and family's social integration.

parents' behaviour

A key theme in relation to behaviour relates to a topic raised earlier (see p25) – the difficulty children have in understanding a parent's mental health problems, especially those arising from severe mental illness. A recent overview of children's experiences (F14) summarises the particular problems for them when their parents act in a bizarre way or put their safety at risk. Examples from three studies include a child confused about why his mother wanted to jump out of a window (A10), a child upset because he could not understand what his mother was trying to say (A4), and children troubled by their parent's sudden tears (D5).

Do parents with mental health problems put their child's **physical safety** at risk? The conclusions that can be drawn about this question have been summarised in the Department of Health training pack on parental mental illness (J1):

- First, the quality of parent-child interactions occurs across a very wide spectrum, from impressive caring to child injury and death.
- Second, there is a clear consensus in the literature that most parents with mental health problems do not pose a physical risk to their children (or to others in their community).
- Third, children's safety has been more at risk in families where mental health problems have been psychotic in nature and have co-existed with other mental health difficulties or those arising from social deprivation.

The studies read for this review reflect the points made above. There are examples of concern about children's safety, but they are raised as exceptions to the overall findings. In one of the studies mentioned earlier (A4), the few examples that arose of children being hurt or frightened by parental behaviour were of children with parents affected by substance misuse or personality disorder as well as by a mental illness diagnosed as severe and enduring. One child's sister had been hit in the past by a depressed mother who had been drinking heavily. Another child was worried about how her mother might behave if she drank alcohol at the same time as taking medication for

her mental illness.

In relation to social deprivation, the study of mothers on social work caseloads (A7, E18) found that the mothers who were both depressed and considered by the agency to raise child abuse concerns (because a child in the family had been abused in the past or a child's name was on the child protection register) were considerably worse off than the other mothers in terms of deprived living conditions, poor partner and family relationships, and a lack of support networks.

More recently, a review for FOCUS (F15) of the research on parental depression concluded that, while the degree of interaction between parental depression and children's outcomes is complex, parental depression should be treated as a signal of concern because of the consensus in the literature about it being a clear marker of increased risk for children. This is particularly so where other risk factors also operate, especially family conflict and socio-economic deprivation.

Where physical safety is an issue, what is the nature of the harm to the child? At the extreme end, reports following child deaths have searched for a link with parental mental health problems. In a file review of 100 fatal child abuse cases (E17) there was clear evidence of parental psychiatric morbidity in a third of the cases, and insufficient information in just under a quarter, leaving almost half the sample showing no such link. In a similar study more recently, of 40 serious review cases (E19), the primary carer in almost half the sample had experienced mental health problems, mostly depression. In addition, over half the cases involved violent adult relationships, pointing to an overlap between the two factors. In such cases children are not necessarily at risk of either death or serious injury, but the finding highlights the importance of taking the issue seriously, in both assessment and service planning.

An overview of other studies of child maltreatment indicates that they do not distinguish between different forms of maltreatment – they focus, rather, on the nature of the parental illness or disorder. They point to an increased risk of maltreatment by mothers with severe depression, parents with schizophrenia who draw their children into their negative delusions, and families where a combination of depression, personality disorder and substance misuse affects one or both parents (F16).

Are parents with mental health problems **less available emotionally** to their children? This is another aspect of parental behaviour that has come under scrutiny, mainly through studies conducted in the USA in the 1980s and reviewed periodically at that time by key researchers (F17, F18). Whilst sounding caution about the findings – given small sample sizes, different methodologies, and the common lack of control groups that characterise the studies – the reviewers point to the wide-ranging difficulties for children of all ages. In the case of pre-school children, there was increased aggression in the children and

inconsistent discipline and control exercised by parents. Parents of school-age children used negative and critical language and they offered their children less encouragement than other parents when working with the children on problem-solving tasks. There was also heightened conflict between adolescents and their parents.

There are positive factors at play, too. Parents, fearing that their severe depression may be emotionally harmful for the children, deliberately distance themselves because they do not understand the importance of talking about how people are feeling (D4). Children of depressed mothers do not fall behind in social competence if the family is middle class and there is a supportive father on hand (E34). Again, individual and family circumstances vary enormously: context is important.

children's behaviour

Parents with mental health problems worry about their children. Their concerns about difficult behaviour are confirmed by some studies, especially where mental health problems are severe – difficult behaviour has been found to be more prevalent in these children than in those whose parents have either physical health needs or mental health needs that are moderate rather than severe (E21). In this Canadian study of maternal depression, the children were aged seven to 13. The children of the depressed mothers and the mothers with other psychiatric problems scored higher for both internalising and externalising behaviour, with two thirds of these 23 children scoring within the clinical range. The researchers concluded – in line with earlier studies – that the children's difficulties were a function of the severity of parental mental health problems rather than of the particular diagnosis of depression.

In a UK study of 24 parents receiving mental health outpatient services and their children aged six to 17 years (A5), over half the parents expressed concerns about their child's behaviour, and most felt that these difficulties had started or become worse since the onset of the parent's mental illness. The wide range of concerns included aggressive outbursts, conflict with peers, delinquent activity, inappropriate sexual behaviour and obsessive compulsive rituals. Standardised measures of adjustment were completed by both groups, with some interesting differences emerging between parents and children about the degree and the nature of children's problems. A third of parents (twice the number of children) assessed emotional and behavioural problems as significantly high. Parents' scores were higher for conduct and peer problems, while children identified emotional and conduct behaviour as most problematic.

The theme of children's behaviour features in the large-scale study of parenting in poor environments (E7). An association was found between a high parental score of tendency to depression and high

scores of difficult behaviour in children. While drawing attention to the finding, the authors stress that the data is not evidence of a causal link between these two factors.

A final point here is about the relevance of people's perceptions as well as their scores on standardised scales. A study showed that depressed mothers considered that their children had significantly more behaviour problems than others, but this was not substantiated by objective measures (in F2). The key to change may come from attention to parental confidence rather than competence.

how children cope

UK studies have little to report about the specific strategies developed by children whose parents have mental health problems. A recent review (F14) that is helpful in distinguishing clearly between evidence about parental substance misuse, domestic violence and health problems (including mental health), notes the gaps in research material about the coping strategies of the children living with parental mental health problems. As a result, it is not clear whether, or to what extent, they use the techniques that are described as commonly used by children in other circumstances – techniques such as avoiding family problems, finding distractions from them, intervening in parents' difficulties, or actively seeking help from others.

A new, Scottish, study (A1) does, however, throw light on the ways in which depressed parents cope, and how their coping style in turn affects their children's behaviour. Depressed parents and their children were more likely than well parents and children to adopt a non-productive coping style or avoidance strategy (worrying, not talking about problems, self blame, wishful thinking) and were less likely to seek external support to help them cope with their family situation. Parents who used these strategies were significantly more likely to have children who used similar strategies. Similarly, parents who used productive strategies (dealing with problems, seeking help, focusing on the positives) were more likely to have children who did the same, when trying to cope with family concerns.

Studies from the USA have explored this issue, also in relation to children living with depressed parents. A key finding in early work with parents and adolescents was that it is not helpful for family members – either parents or children – to retreat into silent and separate corners of their home as ways of trying to cope with bouts of parental depressive illness (D4, E22). A more recent study (D2) confirmed the need for family members to learn new ways of responding to one another. Children were likely to be better adjusted – in terms of displaying less anxiety, depression and aggression – if they used strategies that were aimed at accepting or adapting to the stress of living with a depressed parent. They benefited from finding

ways of taking direct action to change their situation or to change the way they felt about their situation.

Rutter, in his 1985 paper on parental mental health problems referred to earlier (F11), explored the way in which people respond differently to situations, and what seems to influence people's ability to cope with adversity. This represented early reflections on resilience, which Rutter described as 'the capacity of a person to develop positively and in a socially acceptable way, in spite of adversity'. Resilience needed a combination of different elements to be in place – self-confidence, the ability to deal with change and adaptation, and a range of social problem-solving approaches. Rutter's writing mirrored the work of researchers in the USA, pointing to the importance of boosting people's skills at being pro-active about their situation and helping them develop strategies for overcoming feelings of helplessness. The concept is now to the fore in professional thinking (see, for example, F19 and H6).

health – physical and mental

The Assessment Framework provides a conceptual map of key dimensions to consider when assessing children's developmental needs, parenting capacity and family and environmental factors (G10). The dimensions most relevant to this section include health, emotional warmth, and emotional and behavioural development.

during childhood

A snapshot of the UK picture is provided by surveys of child and adolescent mental health problems. Children with parents who screened positive on a mental health screening questionnaire were found to be three times more likely than others to have mental health problems themselves (G13). The connection between child and adult mental health problems is also highlighted in local surveys: about a third of parents of children known to child and adolescent mental health services have been found to have mental health problems of their own (E23). Individual studies provide insights into the impact on the children. Some of these have been touched on already, in the Living Situation section (page 19).

Stress is a common experience. In one study, most of the parents felt their children were affected by their mental illness, and half commented that their children worried a lot. In turn, when the children were asked what worried them, over half mentioned their parent's health (A5). Another study comments on how upsetting it can be for children to be living alongside a parent with severe mental health problems (B7). Children sometimes worry about their parent's difficulties, to the exclusion of worrying about themselves. When

asked how their parent's mental illness affected themselves, as young people, almost half of the 40 children in a third – and recent – study referred only to concerns felt about their parent (A4).

Some studies have tried to measure the degree of the stress experienced by children. A school survey, including children with parents and other relatives with health problems (some of them mental health problems), used standardised scales to measure the children's global depression, self-esteem and quality of life (B5). Those who cared for a relative were rated as significantly less happy about themselves and their life than other pupils: they were more depressed and had lower self-esteem. In another study (B3), young people described their experience of leaving home, temporarily or permanently, because of a parent's mental health problems. The young people stated that their parents were caring and concerned, but that the unpredictable behaviour of parents had had an impact on their own mental health. When asked to explain that impact they spoke of problems that included eating disorders, depression, overdosing, self harm, and physical complaints that caused them stress.

It is the emotional impact on children that tends to be singled out for most comment. In a study of the transition to adulthood of 60 'young carers', the provision of emotional support by young people was judged to be the aspect of care most closely associated with providing care for a parent with mental health problems (B3). There are accounts of how draining and tiring it can be to keep a watchful eye on a parent's mental state, especially when mood swings are a feature of the illness. The child of a mother with manic depression worried that her mother might be fine one day but feel suicidal the next, leaving the child anxious about whether her mother's medication was safely out of reach. Another young person reflected that it would be much easier to do practical household tasks than trying to understand and deal with the psychological aspects of her parent's illness.

This theme is developed in the report of another study, of young people from South Asian families (B4). The caring role was described as providing emotional protection rather than practical support. Children made sure parents were safe and not self-harming. They went back home from school during the day to check on parents, they avoided making plans for their own time, and they acted as counsellors, listening to their parent's fears and anxieties.

The emotional impact of trying to adjust to changed family circumstances is also highlighted – in particular, communicating with one another after a diagnosis is made, struggling with new ways of behaving, and not being able to get through to people with the same ease as before. It often fell to the responsibility of family members to provide support with these emotional upheavals (B1). For children and young people, the stress was particularly high if they felt ill prepared, or found it hard to accept that something was wrong, or were unsure

about how to manage unpredictable behaviour (A5).

Feared or actual loss is another theme in studies. This can be about separation through foster care (A10), or concern that a parent might overdose when left alone (B9), or lost opportunities to enjoy childhood (A4), or worry about a parent's life expectancy or one's own future (D5). A related issue is fear of the unknown. Most parents in the study of parents receiving out-patient mental health services (A5) felt their children did not understand what was wrong with them, hardly surprising since almost half of the children said that no-one had talked to them about that. One child was told she could not visit her mother for a week, but not told that was because she was ill in hospital after an overdose. Another was left at home, feeling rejected, and wondering whether her mother was in hospital or prison. Parents in the study had clear views about what was needed – they did not want children feeling responsible for a parent's illness, or upset by not knowing what was happening, or over-burdened with too much information.

There are lessons from USA studies, too. The FOCUS study mentioned earlier (page 31) explored the health needs of children of parents with severe depression (F15). It reviewed three USA longitudinal studies about the impact of parental depression, and three robust USA studies of evaluated interventions. The impact studies found raised risk of depression in the children of depressed parents and, in one study, a raised risk of anxiety disorders. The intervention studies produced mixed results about the effectiveness of interventions. Group therapy for adolescents who were depressed was no more effective than other treatments (E24), but one-to-one interventions using cognitive behaviour therapy did help reduce the onset of depression in well young people (E25). So, too, did a programme aimed at increasing parental understanding of children's depression (this is the programme referred to as study D4 in this review, and described also in references E13, E14, E22, F17, and F20).

when children become adults

What are the longer-term consequences for children who grow up with a parent with mental health problems? The lack of UK longitudinal data on children of parents with mental health problems makes it hard at present to answer this question. Various qualitative studies (B3, B7) do provide some insights, in that they comment on the physical and mental health problems that some adults attribute to the caring responsibilities they had assumed when they were children. Examples of physical health difficulties include asthma, epilepsy, and hair and weight loss caused by stress. Mental health problems include anxiety, depression, and the fear of not being able to cope with life. These long-term effects were reported more frequently by those whose parent had needed help with mental, rather than physical, health problems. What the studies are unable to do is explain the possible

impact of other factors besides parental mental health, such as social deprivation and exclusion.

USA studies have probed this association between parental mental health problems and the longer-term impact on children. Most of these studies were conducted in the 1980s, and most focused on the adolescent children of parents with severe depression. It was found that such children have a 40 per cent chance of developing a major depression themselves by age 20, compared to a 20 to 25 per cent risk in young people in the general population (D4). In relation to manic depression, a meta-analysis of 17 small-scale studies found that children of affected parents were about three times more likely to develop the illness as children with no such parental history (F21).

Researchers have hypothesised that a combination of influences are at play. One is that major mood disorders have a genetic basis, thus making children more susceptible if parents have been affected themselves. Another is that parental mental health problems create difficulties in parenting – parents may find it hard to be available for their children, attention from the well parent may focus on the parent more than the child, and children may feel isolated and rejected, with the effects lasting longer in some children than in others (F29). A third factor may be that children learn behaviour patterns: as a way of connecting with their depressed parent they copy their mood and then maintain these behaviour patterns throughout life (E13).

Irrespective of these causes – or this combination of causes – researchers on both sides of the Atlantic have argued consistently for more attention to be directed at both the prevention and the treatment of the emerging needs amongst children of parents with mental health problems. In the USA the search for a preventative programme that could be delivered in the community was fuelled by the knowledge that only a quarter of children in need of specialist services were accessing them (E14).

In one UK study of parents receiving mental health services, the mental health needs of many of their children had neither been recognised nor referred to specialist child and adolescent mental health services (A5). Another study (E23) highlighted the need for careful follow up in cases where children do not attend appointments with specialist services, given the finding that children who missed appointments were significantly more likely than others to have a parent experiencing mental illness.

education and employment

The Assessment Framework provides a conceptual map of key dimensions to consider when assessing children's developmental needs, parenting capacity and family and

environmental factors (G10). The dimensions most relevant to this section include education, stimulation, employment, and income.

children's development

Studies about the cognitive development of children whose parents have mental health problems relate mainly to maternal depression, and to post-natal depression in particular. They point to an association between a disturbed mother/child relationship and an adverse impact on the child's cognitive and emotional development (E26), with a higher risk where the mother is also experiencing personal, social or economic difficulties.

Follow-up studies show continued cognitive impairment as children reach school age, with teachers rating the children of depressed mothers as showing significantly more signs of behaviour disturbance than other children (E27). Again, the findings are not exclusively about the depression itself – the researchers report that family social class and the child's gender had the most pervasive influence on adjustment to school, with boys from poorer families the least well adjusted. The researchers argue for resources to support mothers of young children and, in particular, for routine screening and effective treatment for post-natal depression.

Questions about the impact of parental mental health problems on schooling are common features of research studies that seek the views of children and parents. The starting point for some reports is that families and young people demonstrate high levels of commitment to educational achievement (B1), and that school can provide sanctuary for children during periods of family stress (B9). Examples of extra help received from teachers are remembered with gratitude (B7).

On the whole, however, accounts focus on the negative aspects of a child's education and school life. One study (A4) reports that most children in the sample, all of whom had a parent with severe mental illness, had missed some schooling, sometimes linked to fear about what might happen to parents if left alone during the day. Young children in another study (A5) said that one of their biggest worries (second to concern about their parent's health) was about school. They were anxious about getting to school, and about not coping with work and exams.

A national study in 1997 (in B3), of 'young carers' living with parents with a range of needs, including those arising from mental health problems, estimated that just over a quarter of children of all ages had missed school or experienced educational difficulties which the children felt was linked to their responsibilities at home. For children at secondary school the proportion increased to a third, with reports of young people leaving school without qualifications and some not entered for exams by their school.

A later, small-scale study of young adults (B3) indicated a higher incidence of problems than in the national study. Almost half had missed school and a third had no GCSE passes. Young people said they had been reluctant to leave a parent who was depressed or in pain, and in a few cases parents – especially those with mental health problems – had asked not to be left. Some said they missed school occasionally because they felt too stressed to go. But not everything was negative. Two thirds of the young people were in education beyond school age, and several had started or were planning a university course.

Difficulties encountered by children during the school day are also highlighted, with a particular focus on bullying, actual or feared (B2, B5). Researchers explore possible reasons for the problem being mentioned so frequently by children – they speculate, but reach no firm conclusion, about whether the findings indicate difficult experiences of the particular children studied or the endemic nature of bullying in schools. Presumably similar questions could be asked about the reported high rates of absence from school – do the reported rates match school attendance records, and are absence rates higher than those of other children from a similar socio-economic background?

Another concern raised is the poor response of schools to family difficulties (B1, B4). Some young people were fearful that their privacy would be compromised if teachers knew about their circumstances, and others had already been let down in this way, with personal matters raised in the presence of other students. Black young people commented on patronising comments made by teachers, and of no allowance being made for problems with punctuality, attendance and academic performance. More than half had experienced racism, some on a regular basis. This was not seen as being a consequence of caring for an ill parent, but the discrimination that they experienced added to their difficulties and made it less likely that they would seek help at school. A point made by young people in both studies was that they felt particularly let down when schools knew about their home circumstances but did nothing to support them.

Parents, too, were upset about negative attitudes. They felt judged badly for not being able to get to parents' evenings, and they resented the pressure on them to attend a meeting at school as a condition of their child being allowed to return.

Retrospective studies of adults who had cared for parents as children present a mixed recollection of school life. In one study (A10) the prevailing view was they had not missed school itself but they had 'missed out' – finding it hard to make time for homework and social and sporting events. In another study (B7) school was remembered by many as a painful social experience, and academic success had required careful juggling of their time, with long hours of study on either side of periods of crisis at home.

In some of the studies, young people and adults spoke of the impact

on later opportunities. Again, views were mixed. For some, career dreams had been abandoned, entry to college deferred, study restricted to a venue close to home (B4). Others felt their caring responsibilities had equipped them well to get a job they enjoyed (B7).

parents and work

Access to employment is of relevance to parents, too, and there are links here with the earlier section on Living Situation (page 19). In one of the earliest studies of maternal well-being (E4), paid work outside the home was found to be one of the factors that protected women against depression in the wake of a significant life event. Work opportunities for parents do not feature much in the more recent UK studies of parental mental health problems. The point is, however, discussed in one report: only one of the 40 parents was in paid work, and five parents said that their wish to work had been frustrated by discriminatory responses from potential employers (A4).

There are examples of initiatives to improve access to work by people with mental health problems and, though these tend to start from the perspective of single adults using day care services, they can be helpful to parents, too. One local authority conducted a review of day services, found a gap in knowledge about work opportunities, and then led a project with service users to map all the local initiatives that supported people with mental health problems to re-engage with education, training and employment (H7).

It is to be hoped that the government's report on mental health and social exclusion (G5) will promote good practice elsewhere. It makes recommendations about both employment and support for families and communities. One of the action points is that people with mental health problems should have a real chance of sustained paid work reflecting their skills and experience.

some messages for practice

key findings

- Family members – parents as well as children – need to have their fears allayed, and to have access to information, specialist services, support that is consistent and continuous, and the same life chances and opportunities as other parents and children.
- Obstacles to achieving good outcomes for children and parents include a fragmented response by adult and children’s services, a lack of attention to the needs of individuals, and an undue focus on negatives rather than strengths.
- 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.
- A sympathetic response from professionals, early attention to difficulties, support for different family members, a specific focus on particular problems, and using families’ own experiences to identify needs and possible solutions are common proposals for improving practice.

messages from children and young people

When asked what they want – or the changes they would like to see in their life – the response of many children is about their parents, not themselves. They want parents to be well, to be cared for, and to get the attention they need (A5, B1, D5). They also feel that their parents might benefit from opportunities to meet other parents in similar circumstances (D5).

A common request for themselves is for information. They want to understand their parent’s illness – the reason for mood swings, the medication they take, and the causes, symptoms and likely consequences of their health problems (B4, H4). They want to know, too, how to deal with those consequences; the literature abounds with examples of what children have to negotiate. At home, this might be about when to call the doctor and how to identify the onset of difficult behaviour. Out of home, there are problems about what and how to tell friends, relatives or teachers about their parent (B4). Or they might need help to cope with embarrassing behaviour such as when a parent suddenly withdraws a child from school or makes bizarre comments to staff. Some children have made specific requests for information to be age appropriate (A4). Others warn against information overload – children should know that information will be provided as and when they need or want it, rather than having so much detail that they feel burdened by their parent’s problems (A5).

The key for many children is having someone to talk to who will listen and understand (C5). For children this means people who can offer advice and suggestions, without forcing opinions on them,

and adults who can take weight off their shoulders and make final decisions whilst leaving them with some choice about what will happen (F14). A recurring theme here is that people with specialist knowledge of mental health problems are valued highly (A4, F14).

The style of communication is important, too. Children and young people have said that they prefer people who do not interrupt, who make eye contact, who use humour and language they can understand, and who smile and share feelings. Advisers who have personal experience of the family's situation attract particular praise. The anonymity of telephone helplines may have the advantage of helping children retain a sense of control over their life (F14).

Children are hesitant about using formal services because they find it hard to trust them. What makes a difference is being able to access services easily, knowing that someone will still be available next time they are needed, and feeling reassured that contact with an agency or worker will not make things at home worse. Having their views respected is key, too. In one study the young people who were providing care for a parent with severe mental illness spoke of their frustration at being ignored during assessments of their parent's needs (A4). When children are involved in discussions, it is important that information is not passed on without their knowledge.

There is more support for informal sources of help. Children want support from their parents, relatives and friends. They welcome the chance to relax and have fun with others, to feel safe that they are not alone with their problem, or simply to forget about it for a while. The quality most praised in projects for children who are 'young carers' is the opportunity they give children to meet others and share experiences (B11, C5). Continuity during the school holidays is appreciated, not least because it helps relieve the extra stress of children and parents spending long periods together (B6).

Some comment is made about what is wanted later in life, for adults who have cared for their parent as children. One study (B7) reports on four suggestions made by participants, half of whom had helped care for a parent with a mental health problem. They proposed self-help groups so people can discuss feelings and emotions, counselling, a support structure in order to get a second opportunity for study or training, and the chance to influence policy initiatives.

messages from parents

Just as children focus first on parents' needs, so parents tend to start by describing what they want for their children. They want them to feel 'ordinary', in the sense of benefiting from the opportunities enjoyed by other children (B12), and getting early attention if their daily life is disrupted or their behaviour difficult (B4).

Parents recognise that the key to positive outcomes for children is for parents to be supported in ways that will remove the need for children

to be involved in excessive or inappropriate care tasks (H4). A common theme is that parents know that they will remain dependent on children unless and until their own independence is achieved. Whilst a few of the parents in the study of children of parents with severe mental illness (A4) were not troubled by the fact that children were caring for them, others did not want to be so reliant on their help. But there were few alternative options. Their children could provide help that was immediate and flexible. They were available when formal services were withdrawn or proved unreliable. They were close at hand when relatives and friends were distant or critical.

For themselves, parents want to feel accepted for who they are. This is about having their parenting and authority acknowledged and supported, rather than seeing their parental role undermined and their family structure threatened. They want services that take account of their aspirations and their fears. They want help in their own right, so they can discharge the responsibilities they feel towards their children. When asked, parents are clear what they want from this sort of approach. It is about having more open discussion with professionals about their children, and having information to pass on to children at different times and stages of their life. It is also about getting access to extra support for themselves, so they can parent as well as they would like (F22, F23). One study found no evidence of services provided specifically to support parenting, and little mention of these needs in the plans drawn up by social services (B3).

The style of response has also attracted comment. Parents want support from professionals who do not attribute parenting difficulties solely to mental health problems but, rather, see their life as a whole. This may mean asking about, naming, and acknowledging the impact of adverse individual and family circumstances, both past and present (A8, E28, F22). It is similar to the importance people attach to professionals being willing to acknowledge and bear witness to other experiences, including domestic violence (A2), racism (B1, B4) and the trauma of being a refugee (H8).

Practical and emotional support is wanted, too, to help family members understand and communicate with one another, to change the things that can be changed, and to manage those that are more resistant to change. Parents would also welcome reassurance about the negative perceptions they think others hold about them – that they are a danger to their children, are not like other parents, or deserve to be stared at and discriminated against (A4).

Parents want to be, and to feel, in control of their life. This is more likely to be achieved if professionals have had contact with them at an early stage of their mental health problems, rather than intervening in times of crisis, when conditions have deteriorated, and then withdrawing as soon as the danger or panic has subsided. If parents know that treatment services are available, and that arrangements will

be made for their children to be cared for, there is a greater chance of parents feeling less stressed and more in control (H9).

Above all, they want to know that their children will not be separated from them – this is a constant theme in the literature. Parents have identified the support services that would help reduce this risk – they include practical help with child care and household tasks, respite care in and out of the family home, and peer support groups for different family members (F25, H10, C5).

Care arrangements remain relevant even if children and parents do become separated. A review of cases brought before the European Court of Human Rights, by parents with mental illness, clarifies the circumstances in which human rights have been violated. Whilst state intervention is deemed justified if a parent suffers from ‘grave psychiatric problems’, what is not justified is a total ban on contact (because it removes the chance of re-establishing a relationship), or excessive delay in the legal process (because it prejudices the reunification of parent and child), or emergency separation at birth (because the unnecessary distress can cause parental mental health to deteriorate) (F26).

If parents need hospital treatment they would like to see better provision for their children. They worry about restricted visiting hours, stigma, the possibility of other people behaving in a way that might frighten their children, and the lack of family-friendly facilities and activities. They feel keenly that hospital wards are unsuitable places for children to spend time with their parents (A4, A8, H9). It is heartening to note the government’s recent commitment to review – as a matter of priority – the quality of facilities and general attitudes to family visiting in hospitals providing mental health treatment (G5).

Like children, parents want some time for themselves, to relax and follow their interests, alone or with others who may be in similar circumstances or living in their community. They want their children to have similar opportunities for local involvement and activity (B1, C5).

messages from professionals

As this review indicates, there are relatively few studies that have a particular focus on the views of children and their parents with mental health problems. In contrast, there is an extensive literature that draws on the experience and analysis of professionals engaged in policy, practice and research. A review of this material provides a clear picture of what they consider will make a difference to the life chances of children and other family members affected by the needs arising from parental mental health problems. The literature also identifies the obstacles to achieving that goal. Some of these key issues are set out below. Much of what is reported resonates strongly with the earlier messages from children and parents.

assessment and an early response to difficulties

The ability to respond early will reduce the possibility that professionals will feel compelled to exaggerate the risk, to children or others, in order to secure services for a parent with mental health problems (A8, H11). The danger of that approach is that parents who are resistant to service involvement are likely to become even more alienated, and for good reason. When they are seen in a more negative light than is really the case, parents stand less chance of being assessed as a competent parent overall – and needing help in periods of difficulty – than assessed as a parent with a mental health problem that leaves them incapable of providing good care (H9).

An early response must be backed by the potential for early, and focused, action. Professionals are as frustrated as families by assessments that are more about assessing the lack of risk, and so rationing limited resources, than about analysing different people's needs and identifying and offering helpful responses. There is growing dissatisfaction, too, with the proliferation of assessments as people move slowly from one service to the next, and sometimes back again, with a new assessment at each turn.

The frustration is compounded if assessments fail to make links between different aspects of people's lives. In a file analysis of 32 cases in a social services department, just over a third of the mothers had mental health problems (E29). Social workers tended to miss the connection between mental health problems and domestic violence and, hence, the possibility of mental health issues being the secondary rather than the primary problem (E29, H12). In some cases the violent partner came to be seen as the person keeping the family going in the face of the mother's depression or other problem, with his violence and potential risk to the child going unrecognised.

New developments have the potential to deal with some of these problems, at least in relation to assessment. Templates for partnership work between agencies have been introduced in some areas (H4), and other models are being tested as part of the government's drive to improve information sharing about vulnerable children (G1) and assessment of their needs (G14).

Another important aspect of assessment is that those doing the work should start with a clear understanding of mental health problems and mental illness. They need to understand, for instance, that a range of factors can trigger the onset and continuation of mental ill health, that the vast majority of parents do not neglect or harm children simply as a consequence of mental illness, and that mental health problems may result in fluctuations in parenting that can be accommodated by flexible service responses. They need to appreciate, too, the possible contribution of family and friends. People close to the child may be able to provide care and act as role models for children. Relationships can be strong and effective in families with

parental mental health problems. Some children will want to help look after their parent, and doing so will be one way of feeling involved and needed (A4).

If joint assessments are not undertaken by agencies, professionals in adult services need to remember to ‘think family’ in their assessment work. Information should be recorded about whether clients have or have had children, whether they care for or have contact with their children, and the nature and degree of involvement with other services (H4). Genograms should be used routinely, to help clarify people’s connections (E30), and social histories can help identify local support networks as well as reducing the need for families to give repeat explanations of their life history (C2).

a joint approach and family focus

The needs of parents with mental health problems and their children interact in complex ways but often the close relationship between the two is not reflected in the response of health and social care services. Professionals inhabit different worlds of work and they find it difficult to communicate across their different agendas. As a consequence, adult mental health workers appear to child care workers to focus solely on their adult patient, and to be overly concerned about issues of client confidentiality which in turn preclude them from discussing the situation with partners and other family members, including children and young people.

Some of these barriers to joint work have been explored by teams striving to achieve a better response to the needs of all family members (A5, H13). Lack of time and resources may be part of the reason why adult mental health workers miss the importance of seeing patients as parents, and why they fail to create opportunities for regular discussion with the family about the children’s needs. Or workers may hesitate to do this because they feel unskilled in child and family work. They may be influenced, too, by a wish to protect patients from discussing issues that might shake their confidence or add to their anxiety. Additionally, parents may be resistant to such discussion, especially if they minimise or deny the impact on children, or find it hard to juggle their needs and those of their children, or because they hope that keeping the problem to themselves will protect children from being removed from them.

The need for a joint approach by adult and children services is well documented – it is a recommendation that pervades the literature studied for this review (see, for example, A5, A8, C5, E20, E30, F1, F2, F12, F15, F23, F25, F27, H4, H13, H14, H15, J1). The thrust of the argument is that parents are generally well aware of the possible negative impact of their mental health problems, and they are keen to get help for their children. The development of closer working links between services would make it easier to promote awareness of what

is happening to adults and children in the family as well as stimulating discussion about how to remove the structural barriers that exist at present – between services for parents and those for children, between the majority of parents in the community and the minority who need specialist psychiatric services, and between adult mental health and child mental health services. It is hoped that the development of the children's National Service Framework will complement the adult mental health NSF and promote improved partnership working between children and adult services.

A joint approach, it is argued, would be helpful across the continuum of concern felt by professionals and families. At the low-risk end, work that takes a family approach will make it possible to attend to the needs that other children and other adults may have, rather than focusing exclusively on the parent with mental health problems and/or the child thought to be at risk. Early support to a well parent or other close adult is likely to help promote and maintain a child's resilience. Having someone with whom they can talk and identify can help protect children from feeling unduly responsible for the well being of their parent. At the higher-risk end of the continuum, studies of parental psychiatric disorder and child deaths highlight the lack of participation by adult psychiatrists in child protection procedures and the failure of children and family agencies to consider routinely the implications for children of living with a parent with severe mental health problems (1).

The helpful guidance produced for adult psychiatrists (F30) acknowledges the importance of working within a family model. The expectations placed on those working with adult patients include knowing which patients are parents, talking with patients about their role as parents, observing interactions between parents and children and initiating conversations with older children, including partners in assessments, and recognising that it is insufficient to treat symptoms in isolation from the social context of parents and children.

Many arguments have been advanced for needing a family-centred focus. Two are probably key. One is about greater clarity in **identifying the children** who may need help because of a parent's mental health problems. Children and families may present to a wide range of non-mental health agencies, and these services need to be aware of this, know how to respond themselves, and know what resources are available. Put simply, if the children cannot be identified, their unmet needs cannot be addressed.

The second issue is about greater clarity about who is **responsible for the children**. This theme has been well addressed in work across Australia to scope the services available for families (F25). The report comments that adult mental health services are in a good position to ascertain who has mental illness and is also a parent, to offer general support and information to the children, and to call in more help if

needed. They may not, however, be equipped to assess parenting capacity or the impact of parental mental health problems on the child's own mental health. On the other hand, child and adolescent mental health services are well equipped to work with children and families, but cannot do so unless families are referred and do not do so unless needs are quite serious. Other services may be involved, because of co-morbid or multiple problems involving substance misuse, juvenile justice or child protection services. The picture is complicated further because services are seen as fragmented and under-funded, with gaps created by eligibility criteria that determine in a narrow way which agency is responsible for children or parents. Many would see this analysis as applying to the UK too.

In summary, there is a clear message about the need for greater collaboration and integration of child and adult services, and for the development of a more family-centred focus. Parents worry about the lack of attention to their children's needs that can add stress to already vulnerable families. Professionals can get caught up in the deep divisions that are described as stemming from service tradition, history, specialty and geography (A5). More opportunities are needed to increase the thinking about the principles that should underpin a family approach, and about the shift in attitudes as well as working practice that might be needed for this approach to become a reality.

These ideas are not new, but nor have they been implemented. While there have been some developments to bring the work of different services closer together, and there is now a plan to collate knowledge and provide national guidance about joint working arrangements (H16), the move to a combined adult and children's team has remained elusive.

attention to specific mental health needs

People need prompt access to the treatments that are considered effective for their particular problem, and this is as important for those who may have low-level needs as for those whose condition has been diagnosed as severe and enduring. Specific help may be needed to overcome or come to terms with the impact of accumulated difficulties over time, including loss, discrimination and long-term ill health or disability. A holistic approach is needed, one that acknowledges people's role as both individuals and parents. For women in particular, there is a need to identify any past as well as current abuse or oppression and to consider how that might be affecting their current functioning and their wish to parent well (E28, F24). Therapy may be needed, as well as opportunities to develop confidence and self-esteem, and the practical and emotional support that can help them cope better (A8). Where domestic violence is or has been involved, agencies will need to provide protection, advocacy and outreach work. More generally, agencies will need to acknowledge that – especially

where multiple stresses impact on families – long-term help rather than quick fixes will need to be available.

Where parenting is affected, there may be a need here, too, for services that focus on both emotional and practical issues, to strengthen attachments as well as improve skills and confidence in raising children. Early attention to support parenting is advocated in a new review of normative studies, ie those conducted on parents and children randomly selected from community populations as opposed to studies of people receiving a specialist service. The studies were about punishment of children in the home, marital disharmony, and step-parenting (F12).

Parental mental health – and especially maternal mental health – whilst not the primary focus of any of the three studies, turned out to be a significant issue in each one. Mothers with poorer mental health were more likely than others to try and impose control and limits to their children's behaviour, to punish their children frequently, and to have children with more serious bumps, scratches and bruises as a consequence of daily experiences. The author argues that the studies provide evidence that the quality of mother/child relationships is disturbed when the mother is depressed, and she concludes that there is a clear message for service providers – initiatives that act to support parenting and the home environment, including the well parent and others who are involved with the children, would be the most effective in reducing the impact of parental mental health problems on children. If help is offered preventatively, when mental health problems appear in parents, it will help stave off later mental health problems in the children.

For children, the likely need is for creating and boosting resilience. If they develop strategies for accepting and adapting to parental mental illness, they will be more able to achieve independence from their parents as they grow older, and more able to manage well at work, home and in relationships. There is a need, too, to compensate for any developmental and other delays that stem from parental mental health problems and to ensure that protection is in place at the point when, or for the period in which, there is risk of harm or neglect.

The issue of dual diagnosis is relevant here. Attention to mental health needs should not be delayed – as is sometimes argued – until such time as other co-existing problems (substance misuse, problem drinking, domestic violence) have been tackled. People's lives do not usually lend themselves to such a clear separation of the causes, symptoms and consequences of adversity. The association between different factors can be complex, and the direction of the association may not be clear – mental health problems may result in marital discord or they may be a consequence of it; they may be related to childhood abuse or other adversity or they may be a consequence of domestic violence in adulthood (F2, F12).

The important thing is for professionals to harness people's commitment, and reach agreement on what might be worked on and when. There will be an advantage, if more than one specialism is needed, for them to be provided alongside interventions that are already in place, drawing specialists in, to meet people in familiar surroundings rather than referring people on, to cope alone with new and potentially unsettling situations*.

support for individuals and families

helping children live with stress

Learning to live with the stress of parental mental health problems has been one of the main aspects of direct work with children, and the ideas have been developed mainly from USA work (F28). Studies have reported that children have fewer emotional and behavioural problems if they use strategies to accept or adapt to the stress of parental depression, more so than the children who respond by trying to keep their distance or pretending that nothing is happening (D2).

If specialist help for their own difficulties is called for, greater attention should be given to providing a focused and early response – many children with psychosocial problems do not reach specialist child mental health services, those that do are not necessarily the most needy, and long waiting lists are a common problem (E33).

A second type of intervention for children – a combination of information, group discussion and support from a mentor – also appears promising, though the evaluation is less robust (D1).

Thirdly, hospital nurses have been at the forefront of the plea for information to help children cope. Programmes for children whose parents are receiving hospital psychiatric services have been piloted, using group discussion based on a psycho-educational approach. The perceived advantages of this approach are that the work is both safe – because children talk to others who share similar experiences – and specialist – because information about specific illnesses is given by professionals with mental health expertise (D5).

helping parents build family cohesion

Research confirms the important role parents can play in helping their family remain strong and mutually supportive at times of crisis. When parents have practical, and ongoing, help from mental health clinicians they can encourage their children to talk about their feelings and to develop interests outside the home. This intervention was more successful in building family cohesion and children's resilience – even during periods when parents experienced bouts of severe depression – than a comparison intervention which gave parents information only, rather than direct and practical support (D4, E13, E14).

*A recent campaign – about mental health and substance abuse – has argued for both a new kind of professional (to help people navigate health, social care, housing and employment services) and a new kind of service (Connected Care Centres where people can self refer to a co-ordinated professional team). (H22). The ideas are similar to those that underpin the family mental health service set out on page 58.

This work shows how parents are seen to hold the key to relieving their child's emotional stress. This is more likely to happen if parents are willing and able to respond to their child's pain in an accepting way – even if their mental health problems and their accompanying behaviour have caused that pain. Learning to talk about emotions together, and over time, strengthens connections between family members. It brings people closer together during episodes of mental distress, rather than each being alone with their confusion, anger or guilt. Strong family relationships enhance the child's ability to move to independence without worrying unduly about their parent's needs.

These ideas were piloted and then developed into a USA programme called PIP – the Prevention Intervention Project (D4). Evaluation showed improvements in the young people's understanding that they were not to blame for their parent's depression, and in their interpersonal relationships and capacity to move on in their life outside the family. The PIP programme has been adapted recently for use in the UK, with promising early results in terms of more balanced interactions between family members, and – for children – improved social functioning (C2).

The children were developing the ability both to reflect on their feelings and what was happening at home and to increase their involvement in interest groups away from home. Parents had been fearful of the consequences of including child care professionals in family discussions about their mental health problems, but the evaluation confirmed that their fears had been unfounded, and that they were enthusiastic about the help offered.

Information about practical matters is important, too, not least because welfare benefits can be hard to understand and claim (B2). Ways of targeting advice to people with mental health problems have been tried and tested. A study to examine the value of integrating citizens advice bureau sessions with health care services reported an improved sense of vitality and mental well being in users of the service. There was particular value in getting advice from a familiar setting – such as the local GP surgery – where patients with mental health problems felt comfortable with surgery staff and felt less stigma than in other public places (H17).

Continuing attention is needed, too, to help reduce the adverse impact of people's personal and social circumstances. Family members do not expect professionals to produce magic solutions to intractable problems, but they do value workers who stand alongside them over time and are willing to acknowledge and help tackle the disadvantages that stem from poor housing, poverty and unemployment, social isolation, conflict in relationships, limited leisure and educational opportunities, inaccessible services, and racial and other harassment (B1, C5, E12, H11, H18).

strengthening and supporting family networks

Attention to the needs of well parents and other people close to the family has long been advocated. This may include ongoing contact with specialist mental health professionals involved with either adults or children in the family (E20). More usual, however, may be the experience of well parents who feel alone and unsupported, with no-one to talk to about their feelings and anxieties (A8). Other trusted adults can supplement the resources and the energy of the well parent (F22), but it should not be assumed that relatives and friends will always know what is needed, or that they can provide it without having access to advice or support for themselves. They might, for instance, need help with the words to use when trying to explain mental illness to children of different ages and ability (J2). Nor should it be assumed that they will ask for the help, no matter how desperate their need – they may be reluctant to do so, for fear of being deemed incompetent (A8).

They, too, may need information. Doctors can help people understand what young people need to know and they can offer to pass on that information themselves. Knowledge, even about difficult or unpleasant things, can be reassuring, and care should be taken not to patronise young people as being too young to know what is happening or likely to happen. For families fearful of losing their children, knowledge can make all the difference to their ability to understand – and if need be, defend themselves – against over-intrusive or unnecessary intervention.

learning from users

The reasons for involving users, and those with mental health problems no less than others, has been well rehearsed. Users can identify the attitudes, structures, and financial and other barriers that prevent services from being used. They can pinpoint the non-stigmatising aspects that should be enhanced. They can evaluate new practice, and help providers think in different ways. They can advise on the importance of accessible information, and help to produce and disseminate it (H4).

One study brought together two important principles – that lay people have expertise in defining needs and solutions, and that users should be involved at the start of developments, not just consulted once policies have been formulated and are about to be implemented (E12).

The researchers interviewed residents in two constituency wards, to ask people about the main sources of mental distress and the place of primary care counselling as a potential service response. Overall, across all ethnic groups, stress resulted from family relationships, unemployment, debt, parenting difficulties and fear of crime. For the Asian residents who formed two-thirds of the sample, racism was one

of the most important issues. Over half related experiences of racism, and these had had a marked and wide-ranging impact – on their social life, their use of services and their general mental health.

Two-thirds of the sample, including three-quarters of the Asian residents, did not think that counselling was best provided from a GP base. This was because of their GP's gender, ethnicity, social status or language, or because the doctor's knowledge was felt to be limited to medical matters. Young people were wary of getting any advice from people they knew – including GPs – in case their parents found out. Recommendations about services included accessing counselling through existing advice or advocacy workers, as part of a wider provision of neighbourhood support. Another strong message was that counselling providers should be aware of the social context in which mental distress is experienced, and of the effects of living in disadvantaged areas, with the fear of crime, racism and poor services.

Another study (B1) highlighted what users want. Families valued services that offered flexibility, choice from a range of support options, respect for family wishes, and an appreciation of different ways of organising family life and parenting. Their discussions – parents and children talking together, as well as in separate groups – raised the importance of professionals drawing out the points where family views coincide and, in cases where they diverge, of seeing how conflict might be avoided or resolved. They argued for assessments that addressed the potential sources of tension in families so that children's rights can be supported in the context of family rights. They also wanted their strengths used more, with themselves having greater participation in service planning, and with service providers having greater partnerships with the community, including the religious organisations that were supporting families.

achieving a cultural shift

For all of the above to work well, in the sense of providing good outcomes for children and their parents with mental health problems, there needs to be something of a sea-change in thinking and practice.

Compared with 12 other European countries the UK places undue focus on crisis, acute mental illness and child rescue, and insufficient emphasis on prevention, early intervention and family support (E31). Services to provide general support to families, and specific help for particular mental health needs, are less in evidence here, and the thresholds for specialist services are set so high that they are beyond the reach of families whose needs have not become acute.

There are differences in attitude, too. UK professionals are more likely to assume that the family will provide for itself, without outside help, and they are more pessimistic about the chances of change in families. Unlike their colleagues in mainland Europe, they adopt a non-interventionist approach, expecting families to view the offer of

services as intrusive, and so hold back until compelled to act by the onset of crisis. They also make less reference to school as a network for supporting children affected by parental mental health problems.

Another European study highlights the importance of positive attitudes to families (D6). Its starting point was the assumption that new mothers with severe mental health problems can cooperate with professional workers, and will do so if they can see that professionals are committed to responding to their needs. Receiving continuity of care from a known and trusted health worker is a key part of this approach. It is an approach recommended in UK studies, too – a consistent worker to coordinate services, and a firm assurance that every call for help will be responded to, were important features of a community service (A5).

These research messages may seem uncontroversial, but they tend to be missing from UK mental health practice, either generally or in services intended to address specific needs. Personality disorder is a case in point. Parents diagnosed with this disorder are particularly vulnerable to being viewed and treated negatively. Many who experience it are acutely aware of being discounted as not amenable to treatment or change (G15). In one study, mothers with personality disorder picked up this negative attitude and, as a consequence, were reluctant to use services. When a crisis arose that forced them to make contact, they found that the pessimism associated with the diagnosis became a self-fulfilling prophecy (A8).

Yet some projects have found a way out of this mindset. A programme to boost family resilience and communication is proving successful for parents with a range of serious mental health disorders, including personality disorder (C2). Other studies have concluded that giving people the opportunity to discuss their needs with a responsive and sympathetic professional helps build a firm foundation for effective professional intervention (D6).

Another helpful response is to start from the belief that parents want to do their best for their children and have views about how to do that. A logical conclusion is to start with the family's solution and work with any dilemmas and contradictions that arise. This was the message underpinning the government's commitment to good practice with carers (G6).

One practical application of this approach is the use of Family Group Conferences (FGCs). The model is being used increasingly, and in some agencies is now a routine tool when family breakdown seems likely. Unusually, the adult mental health service and social services department in one county (Essex) have combined forces to use FGCs in their work with families with a mentally ill adult (C1). It was introduced because of the high proportion of children in touch with social services on account of parental mental health problems. The model, imported from the Maori community in New Zealand, turns

our traditional planning process on its head in that it invites family members to develop a welfare and protection plan which professionals are asked to endorse and support. The main theme from an evaluation of the first year of the Essex project is that the FGC approach strengthens family networks and provides joint ownership of the planning process by mental health service users, families and professionals.

A final aspect of discussion about attitudes is about the effort put into engaging with parents who resist contact with services. A helpful approach here is for professionals to deem it their failure – rather than something lacking in parents – if people do not engage with them. The challenge is to find new ways of drawing people in. Assertive outreach, visiting people at home rather than expecting them to travel for appointments, has been found to make a difference. So, too, has informal telephone contact rather than relying on letters, the provision of crèches and other child care facilities, and a willingness to accompany people and introduce them to services rather than expecting them to find their way alone (C7).

Of particular importance is the extent to which services seem attractive to potential users – a key question for service commissioners and providers to ask themselves is what might deter them from using their own service, especially as a black parent, or a lone parent, or a father, or a disabled parent, or a refugee with little or no English. Similar reflections can be helpful when trying to reduce the drop-out rate for services. It should not be assumed that all parents can benefit from the service on offer. A danger of that approach is that parents may be blamed for their failure, rather than questions being asked about the appropriateness of the programme (C4).

There is a crucial role for staff development, to tackle the attitudinal shifts required, as well as to upgrade professional knowledge about mental health issues and to instil confidence in assessing need, identifying desired outcomes, and offering services informed by evidence of effectiveness. Training has been highlighted as useful, especially when it provides opportunities for joint sessions across disciplines and agencies (J3, C5), or for reflecting on how services are organised in other countries (E31), or for gaining new skills in working with parents (C3, C6).

This brings us back to the importance of combined work by adult mental health and child care professionals, with their shared work and responsibilities underpinned by a clear and explicit family focus. Pilot schemes may be helpful in the first instance, with robust evaluation to track progress, but then followed by longer-term funding so that the lessons learnt become embedded as part of revised mainstream services, to avoid the pitfalls that tend to beset one-off initiatives – their piecemeal development, vulnerability to changes in staff and funding, and the problems involved in sustaining momentum (E31).

‘think family’ – messages from good practice

In the introduction to this review we quoted Göpfert’s plea for an end to service responses that treat individuals in isolation from their family. Writing at about the same time – reviewing the research evidence on parental psychiatric disorder and child maltreatment – Falkov expressed a similar sentiment:

‘Working together to ensure adequate support for multiply disadvantaged, mentally ill parents and effective protection and optimal development of children requires a shift in approach and conceptualisation of services to encompass a broader perspective in which the health and social care needs of children and their ill parents are addressed’ (F16).

As stated earlier, these aspirations are not new, but they remain an elusive pipedream. One of the main problems seems to be that implementation requires partnership work, not just across agencies, but also across separate divisions within agencies. In relation to mental health work, it has been particularly difficult to bridge this gap between services for adults and those for children.

At a national level, some of the obstacles may be in danger of becoming more difficult to disentangle, in light of the recent government initiatives to bring together the different strands of health and social care for children. There may be specific local problems, too, especially those stemming from geographical distance in rural areas. A different obstacle is scepticism about the prospect of making progress through structural change in service delivery. This sort of solution to inter-professional issues has been promoted for a long time – as, for example, in services about child protection, about youth offending, and about children with disabilities. Ideas stem from a desire that no-one can argue with – the wish for a more holistic, integrated, user friendly and user informed service, but the whole jigsaw we want to piece together is big and complex and constantly on the move. New ideas present new challenges and, before one idea is implemented – and certainly before it has been evaluated – the world has shifted once again.

Yet a compelling message remains: it is unhelpful to retain the separate focus, the separate expertise and the separate practice in adult teams and child care teams that are features of both child welfare and psychiatric work. There may not be a single solution to this dilemma, but it behoves us to keep looking for ways of working that are helpful to the families affected.

key findings

This review of the literature suggests that local responses should aim to do the following:

- combine the skills of practitioners from adult mental health and children and family services.
- take a preventative approach, intervening early to boost people's ability to cope with life's ups and downs.
- assume that parents will be willing to engage with professionals if the service on offer is sensitive to their concerns, family background and aspirations.
- provide direct work with different family members, building on family strengths and equipping children with skills that will enhance the prospect of positive outcomes.
- enable parents to go beyond recovering positive mental health, so that they have the confidence, support and resilience to play the part they wish to as citizens in their community.
- influence the future development of mainstream services, such that a holistic family response to need becomes the normal approach within and across agencies.
- include robust evaluation, so that more can be learnt about what works for children and families when parents have mental health problems.

We describe on page 58 the outline of a family mental health service that is underpinned by these principles (Hg). It is intended to provide an early response to needs arising from adult mental health problems. It can be triggered at the initial stage of involvement by child care services, as well as when parents with mental health problems are using community mental health services. As such, it is not intended as a specialist service but as a normal early response by statutory agencies to children's needs.

The success of the service will depend in large part on the style of work that is developed. Structure is important, but so is process. Some of the key messages from existing good practice models are about the use of a partnership style of working with families, of early responses, and of staff who both want to, and can, incorporate this approach into their work.

testing new ways of working

If the structure of teams cannot be shifted locally, there may be opportunities for testing new ways of working, or for developing responses to particular needs. The following chart provides pointers to some of the promising findings on discrete issues that have emerged from this review of impact and intervention studies. The list is not intended to be comprehensive but, rather, to indicate good studies with which to start.

topic	main studies	other references
parenting	A1 C4 C6 C, D2	E10 E11 E33 F1 F9 F12 F16 G11 H3
adult relationships	C3 D4	F1
family communication	C2 C5 D4	E13 E14 E22 F1
domestic violence	A2	E8 E28 E29 F13
dual diagnosis	C2 C5	F1 F2 F5 F6 H4 H22
services for black families	A6 B1 B4 C5 C6	E12 H8 H21
services for children	A4 C2 C5 D1 D5	E24 E25 F1 F14
starting with family solutions	B1 C1 C6 D3	E33 F3 F4
community-based services	C6 C7 D3 D6	E7 H1 H5 H9 H22
training of professionals	C3 C5 C6	E31 E33 F3 F4 J1 J3 J4
bridging the gap between adult and children's services	A5 A6 C2 C5 D6	E30 F1 F27 H9 H13 H15

outline of a family mental health service

This proposed service (H9) was developed by Greenwich Council, Greenwich PCT and Oxleas NHS Trust in 2003, to promote a new way of working across professional and agency boundaries. The project was inspired by the wish to provide early and effective services to help improve outcomes for children and families in a deprived, inner-city area where parents with mental health problems are over-represented in child protection registrations and care proceedings. The National Children's Bureau oversaw the development phase of the project, and charitable funding has been secured for three years.

needs – who is the service for?

It is for any family where the parent is receiving services from a Community Mental Health Team under a Care Programme Approach and/or where the children/family have been the subject of an Initial Assessment by Children and Family Services. The new service will not necessarily provide the specific service needed in every case, but it will play a crucial role in ensuring that each child and family do get what they need – this might be, for instance, by offering consultation to schools and other referrers and ensuring that help is provided by them.

children

Those likely to have particular needs, or likely not to be receiving a service within the current service framework, include:

- children who may be at risk of neglect or abuse as a result of their parent's illness, but this hasn't been identified by adult services
- children who are just below the threshold for social services intervention
- children for whom the mental health condition might be familial
- teenagers.

adults

Those likely to have particular needs, or likely not to be receiving a service within the current framework, include:

- parents with common mental disorders – neurosis, depression, anxiety
- black and minority ethnic families and refugees/asylum seekers
- those with dual diagnosis, for example, mental health + substance misuse
- parents whose children have been removed from their care.

Access to the service will be open, not just through agency referrals, and will be one where relationships with families can be built and consolidated over time.

outcomes – what is the service expected to achieve?

- Change (for parents with depression) or stability (for those with more enduring mental illness) will be sought within six months to one year from the point of referral, with follow up to monitor which developments sustain at 18 months to 2 years.
- Children remain with parents, other relatives or family friends, or live independently and in contact with parents, other relatives or family friends.
- Children removed from their parents remain in contact with them.
- Parents are better able to cope with factors that contribute to parental stress, eg. housing and finances.
- Parents recognise the impact of parental mental health needs on their children and can take early action to cope with recurrent onset of symptoms.
- Older children have a clearer understanding of their parent's needs.
- When there is risk from parental behaviour that stems from parental mental health needs there is explicit recognition of this and the risk is appropriately managed, including ensuring that children have alternative and consistent sources of adult support.
- Parents are less isolated.
- Children have increased ability to make peer friendships.
- Children are less burdened by adult roles and responsibilities.
- Parents and/or children have developed resilience and acquired coping skills.
- Parents and children benefit from at least one educational or vocational opportunity that would not have been available had there not been a referral.

service – what will be provided?

The service will have six elements:

- a advice and information
- b planning in partnership
- c specialist services
- d social support
- e practical help
- f staff development.

a and b will be located in one place, which may also be the location for some, but not all, of the services in c-f. This will depend on the area's geographical make-up and transport systems, and also recognises that the service should build on existing provision and should have a key role in establishing a network to ensure that services are taken up effectively and are co-ordinated well, so that they complement each other.

a advice and information

A communication team or unit will create a network of service providers, build and maintain a database for use by all services, and provide events and other activities to help foster good working relationships. Ensuring good co-ordination of services will also be part of their role. The information base and feedback from families will feed into strategic forums across children and adult mental health services.

The team will also provide information and advice to families: for parents, to help them understand what is available and how to access services, and for children, to help them understand the nature of their parent's illness. A key function of this role will be to provide reassurance and allay fears, by giving information about the role and processes of the existing mental health and children's services. They will draw on the expertise of the specialist professionals who are part of their team or linked to it.

Joint events will be held for professionals and families, to ensure that there is a framework for parents and children to give feedback about services, offer ideas, be consulted about new developments, and share ownership of the network.

An important principle from the outset will be a commitment to creating an ongoing dialogue between families and the team.

The team will also have a brief to promote positive mental health and help address the stigma that attaches to mental health problems. This work might include creating a local forum – for residents as well as people who experience mental illness and those who deliver services – so that awareness can be increased and the unmet needs of parents and children identified.

Staff skills needed – managing and disseminating information, use of database, networking with organisations, and communication and direct work with children and parents, including advice giving. Staff can be drawn from people currently working in either adult mental health or children's services, or from other professional backgrounds.

b planning in partnership

This team or unit will provide 'Planning Partners' who will work with parents, their children and other key family members to draw up plans for managing their individual circumstances and making best use of services that are available. Two key functions will be first, the use of Family Group Conferences to ensure that family solutions can be implemented, and second, contingency planning to ensure that families can plan ahead for periods of ill-health.

Planning Partners will not replace current assessment services in either adult mental health or children's services, but they will need to establish a very close working relationship. A key responsibility for Planning Partners will be to raise mental health awareness in both child and adult assessment services, so that staff are better able to refer appropriately and to remain involved with the family if that is beneficial.

Parents should have an element of choice about which member of the team they work with, an important aspect of building trust and confidence.

Staff skills needed – an adult mental health social worker, a social worker from a children and family background, a community psychiatric nurse, a psychologist and a Family Group Conference co-ordinator. If possible, it should also include a family therapist. The psychologist and family therapist would help deliver the specialist services.

c specialist services

For parents, the specialist services will include a range of therapeutic services, including individual therapeutic work and support groups, drawing on current services and filling the gaps by commissioning additional services as necessary. The database and network described above would ensure that specialist services respond to changing need.

There is likely to be a gap in treatment services for parents with common mental disorders such as anxiety and depression. The therapeutic services needed are likely to be brief psychological therapies, especially those that use cognitive or behavioural therapy methods, as these have been found to be of benefit in the treatment of depressive illness in community settings.

For children, the specialist services will be designed for those whose behaviour or emotional well-being has been severely affected by parental ill health. There will also be individual and group work around resilience and coping skills. Where there is risk of abuse or neglect close links will be maintained with the child protection service.

The specialist services will provide opportunities to do joint work with parents and children together (including the well parent and/or other close adults) about the impact of mental health needs on family life. A particular focus will be enabling parents to improve communication in the home, with a view to encouraging children to develop outside interests and so give young people permission to move towards independence without worrying unduly about their parent's difficulties.

d social support

A range of services and activities will be available, some for families, others for children only or parents only. Some of the events will be held at the location of the teams or units providing the **a** and **b** services, to help build an identity for the service. The following activities might well be needed:

- Groups and classes for adults, some on a drop-in basis, some with a specific interest element or to develop skills to boost employment opportunities.
- Groups and fun events for children – homework clubs, play schemes, trips, peer support.
- Family events and shared interest groups, such as consultation events or creating a newsletter.

- Parents will work with team members to plan and run these activities, to help engender a sense of joint ownership.
- Child care facilities should be provided for all activities for parents, and attention paid to when groups take place, eg during school hours.

e practical help co-ordinator

This person will have responsibility for organising basic practical support, including help with child care, help taking children to and from school, help in the home (such as at stressful times of the day like tea time/bath time), respite outside the home (eg. with a child minder), and linking with the fostering service to identify respite and longer-term foster carers who can be linked to individual children and families to ensure consistent support. A flexible budget will be needed for transport costs and for sensitive interpreters as needed. The budget might include contributions from both children's services and adult mental health services.

f staff development

The team will have responsibility for ensuring staff development throughout mainstream and voluntary services, in order to increase the knowledge basis about both parental and child mental health needs.

evaluation – how will change be measured?

Evaluation should be rigorous, with those receiving a service matched with families in receipt of a different service from another area or team. Children and parents will be involved in evaluation design and implementation. A clear distinction will be made between the evaluation of outputs and outcomes.

Output measures are likely to relate to:

- numbers completing an agreed programme
- reduction in the number of unplanned placements
- reduction in the length of stays away from home.

Outcome measures are likely to relate to:

- reduction in parental depression, or stabilisation of mental illness
- the quality of parent/child relationships
- parental and child resilience and self esteem
- school attendance and educational achievement of children
- educational and/or employment achievement of parents
- parent and child satisfaction with the service and style of delivery.

implementation

Effective implementation will require strong leadership from a senior manager supported by local authority elected members and assisted by a small multi-agency implementation steering group of senior officers from participating agencies both statutory and voluntary. A service co-ordinator at Principal Officer level will have responsibility for developing and leading the different strands of the service.

Close links with external evaluators and practitioners, and with family members, will be helpful.

summary chart of the main studies

the nature of the evidence

At the start of this review readers were reminded of the importance of approaching research with an enquiring mind. Despite advances in the planning and delivery of social care research, weaknesses remain, because of the state of knowledge that underpins research or because of more practical methodological problems such as organising a sample of the families whose circumstances, problems and needs are of interest to researchers.

Some of the questions to bear in mind when reading the following research summaries, and when using them alongside other sources of evidence in order to develop service responses, are as follows:

what is the sample size?

Some studies have very small samples. The smaller the sample, the more limited the conclusions that can be drawn about the statistical significance of findings or the extent to which they are representative of other families in similar circumstances.

what is the study timescale?

Retrospective reports, as of adult memories of what happened in childhood, are subject to a variety of sources of error. Prospective reports have the advantage of tracking how circumstances may change over the course of a parent's ill health or as a child simply grows older, but such longitudinal studies are costly and time-consuming and so fewer in number.

what is the location?

Some studies listed are from other countries. Lessons can be drawn from the experiences of families and practitioners from elsewhere, but care should be taken before generalising from one place to another.

what is being evaluated and how?

Studies need to be clear about what they are measuring, and how. Findings are more robust if change has been measured over time, preferably before and after the intervention and with follow-up some time later, to see if change has been maintained. Analysing different perspectives is more robust than relying on single accounts of what has happened or been achieved. A control or comparison group adds robustness, too, because comparing outcomes for similar groups of people who have received different interventions makes it more likely that change is linked to the intervention rather than to any other variables.

Where information was available in research reports, we have included details of these evaluation issues in the summary reports below.

A impact studies - mental health

	date	first author	* key practice issues
A1	in press	Cogan	* the links between the coping strategies used by parents with depression and those used by their children
A2	2003	Humphreys	mental health services after domestic violence
A3	2003	Stanley	mothers with severe mental health problems; child protection services
A4	2002	Aldridge	parents with severe mental illness and children with caring responsibilities
A5	2002	Stallard	use of mental health services by parents and children
A6	1997	Green	perceptions of professionals and black families of mental health and child protection services
A7	1997	Sheppard	maternal depression in social work cases
A8	1997	Davis L	parents' views of local services
A9	1993	Hugman	parents' views of mental health services
A10	1992	Elliott	children now adult with past caring responsibilities for a parent with mental health problems

B impact studies - mental health and other issues

	date	first author	* perspectives
B1	2002	Jones	children, adults, professionals – mainly black families
B2	2000	Bibby	children
B3	2000	Dearden	young people – of transition to adulthood
B4	1999	Shah	children – South Asian families
B5	1999	Strathclyde Centre of Disability Research	* children
B6	1999	Centre for the Child & Society	children, parents
B7	1998	Frank	children (some as adults)
B8	1996	Walker	children, parents
B9	1996	Newton	children
B10	1995	Frank	children (some as adults)
B11	1995	Dearden	children, professionals
B12	1995	Dearden	children, parents, professionals

* an asterisk denotes use of a comparison group and/or measurement of change via pre- and post-intervention scales

C intervention studies – UK

	date	first author	*	key practice issue
C1	2002	Mutter	*	making plans via Family Group Conferences
C2	2002	Place	*	CAMH-based service for depressed parents and their children
C3	2001	Simons	*	couple relationships after birth
C4	2001	Barlow	*	parenting programmes and maternal mental health
C5	2001	Rhodes		whole family service for parents with severe mental health needs
C6	1998	Davis H	*	community service for families
C7	1998	White	*	community service for families

D intervention studies - other countries

	date	country	first author	*	key practice issue
D1	2002	USA	Orel	*	support and mentoring for children
D2	2002	USA	Langrock	*	children's ways of coping
D3	1999	USA	Bond	*	groups for socially excluded mothers
D4	1997	USA	Beardslee	*	family communication
D5	1997	Canada	Garley	*	groups for children
D6	1992	Denmark	Lier	*	service links after birth, via infant psychiatric hospital unit

description of the main studies

The following descriptions use the authors' terms for mental health problems. The ethnic composition of samples is included if found in the study report. The date given relates to when the study was conducted or, if not available, to the study publication date.

A1

Cogan N, Riddell S and Mayes G
2003. Glasgow, Scotland

mental health problems

Diagnosed affective illness (severe mood disorder).

what was studied

- How parents with affective disorder coped with their family situation, how this differed from 'well' families, and whether there was a relationship between the coping styles used by affective and well parents and their children.

sample and recruitment

- 20 parents (12 mothers and 8 fathers) receiving a mental health service (but with no drug or alcohol problem) and 20 adolescent children still at home.
- Recruited through community mental health teams.
- Ethnicity – white Scottish.

methods and evaluation

- A comparison group included 20 children and 20 parents – not diagnosed or using mental health services – matched for age, sex, education, ethnicity, socio-economic level and marital status.
- The short version of 2 scales developed by Frydenberg – the Adolescent Coping Scale (measures 18 coping strategies and 3 coping styles) and the Coping Scale for Adults (measures 19 strategies and 4 coping styles).
- Semi-structured interviews about how people coped with family life.

key findings and conclusions

- Parents with mental health problems and their children are more likely to use non-productive coping styles and are less likely to seek support from others, compared to well parents and their children. Children were more likely to blame themselves for their parent's difficulties, and less likely to contact others, through fear and isolation. If parents are not coping well their children are less likely to cope effectively.
- Parents who used productive strategies and shared their concerns with others were more likely to have children who used such coping styles.
- Children of affective parents were more likely to link difficulties at school with their parent's situation and had reservations about discussing it with teachers. Few were involved in discussion with health workers.
- The experiences of children and parents lend weight to messages about good service responses, including early intervention, supporting family relationships, providing age-appropriate information, mental health promotion in schools, and services with a family focus.

A2

Humphreys C and Thiara R
2003. England

mental health problems

Severe emotional distress that often fitted a pattern of symptoms associated with depression, post-traumatic stress, and/or self-harm.

what was studied

main research project: The issues women and their children face when leaving a violent relationship, including attitudes of legal, health and welfare professionals. The views of children and women about the role of outreach services.

for this article: Women's experiences in relation to their mental health – a strong theme in the main study. The mental health services included in-patient psychiatric care, hospital A&E departments, GPs, community mental health services, and voluntary sector agencies.

sample and recruitment

- 180 women from 14 projects (affiliated to Women's Aid, England) that offered a non-refuge-based domestic violence intervention service. Included 6 specialist projects: 2 for children, 2 for black and minority ethnic women, 2 in rural areas.
- Ethnicity – a quarter were Asian and from other minority ethnic groups.

methods and evaluation

- Questionnaires, completed with support from project workers.
- 20 in-depth interviews (including 4 black and minority ethnic women).

key findings and conclusions

- The women articulated a direct, causal link between their problems and the violence and abuse they were suffering.
- The medical model of health was experienced as unhelpful and left women fearful of losing their children – the model included trauma not being recognised, an exclusive focus on the woman, victim blame, and an emphasis on medication rather than counselling.
- Helpful approaches were identified – staff naming domestic violence and actively asking women about it, planning for safety, responding to specialist needs, and direct work to help women recover.
- The key to successful work is a sensitive, non-stigmatising service underpinned by belief, non-judgemental attitudes, and time to listen, understand and support.
- (Main study) – black and minority ethnic women were significantly more likely than white women to suffer substantial problems more than 6 months after leaving a violent relationship.

A3

Stanley N, Penhale B, Riordan D, Barbour R and Holden S

2003. North-East England

mental health problems

Mothers with enduring mental health problems experienced during the previous 18 – 24 months. Included depression (3), psychotic disorder (3), manic depression (2), personality disorder and schizophrenia (2), mental health problem (1). Several partners also had mental health or substance misuse problems.

what was studied

- Mothers' views of their needs and how to meet them, and the views of professionals. The study was fuelled by the wish to understand the response of health and social care agencies to two contrasting sets of needs (mental health and child protection) in families.
 - Inter-professional communication, service organisation and risk assessment, and the barriers to communication and collaboration between practitioners and agencies.
- The resources valued by users and professionals.

sample & recruitment

- Families, all on benefit, from 2 local authority areas of high unemployment and deprivation. Four families had 4 or more children. Only 3 families were intact – the other 8 had children in care or adopted from care.
 - Most mothers were recruited to the study by the authors' contacts in health and social services.
- Ethnicity – white UK.

methods & evaluation

- A qualitative analysis of interviews with 11 mothers with severe mental health problems – the first interview about their background and experience of services and the second, 6 months later, about their needs and support.
- A postal questionnaire sent to 500 professionals in health, social services and voluntary organisations in the 2 areas – about their attitude to families, their views about services, and their experience of inter-professional work.
- The survey was informed by a pilot study of 13 mothers, plus 3 inter-professional focus groups about their experiences and perceptions of casework when mental health needs combined with child protection concerns.

key findings & conclusions

Mothers' views of mental health needs There was a strong association between depression and poverty, and most were experiencing domestic violence, relationship difficulties and problems of access to children.

- Loss was a major source of stress, affecting 8 of the 11 mothers. It included death; the loss of the parenting role when children were accommodated; lost relationships, networks and activities because of children's behaviour; and having a child with disabilities.
- Half the mothers said their problems had emerged before they were 14. All but 1 had been abused as a child – mainly sexual abuse – and this was a factor in their poor mental health.
- The fear of the loss of a child was acute and made mothers reluctant to accept help. Contact with an absent child was hard to accept and hard to manage.

Mothers' views of professionals Those valued most listened, understood, and were not judgemental (resource centre workers and mental health social workers). The least valued (GPs and social workers) were not accessible and lacked understanding. Re social workers – trust was absent, communication was poor, and mothers felt judged and under scrutiny. Re mental health staff, psychologists, community psychiatric nurses and counsellors – the therapeutic relationship helped resolve past trauma and promote self-esteem.

the views of professionals

- Advocacy was seen as part of their role (except GPs and the police) but social workers said they were advocates for the children, not the parents.
- Not all included active listening as what they do or should do – this was especially true of social workers (16 per cent). Important attributes were seen as supporting parenting, treatment, emotional support, and a positive attitude.
- Joint training was seen as a key means of understanding the roles of mental health workers and the impact on children of mental health problems.

services - researcher views

- The criteria for community mental health services were inflexible and tight, family support hard to access, and the lack of child care provision a barrier to taking up services.
- A mental health worker and a child care worker should be attached to each case.

A4

Aldridge J and Becker S
2003, Britain

mental health problems

Parents had severe and enduring mental illness and were getting support via the Care Programme Approach – CPA – (a co-ordinated package of care oversight plus access to a psychiatrist and other services through a multi-disciplinary team). 17 parents (of 40) were self-harming, 27 had attempted suicide, 26 had been hospitalised more than once, and 17 had been sectioned under the Mental Health Act.

what was studied

- This was the first in-depth UK research study of children caring for a parent whose illness was at the serious end of the mental health continuum.
- The study was about cyclical changes in parental behaviour, outcomes for families, professional approaches, and relationships between families and professionals.

sample and recruitment

- 40 families – parents and children – and key professionals.
- The children were recruited from Young Carer projects and projects run by the National Schizophrenia Fellowship.
- Ethnicity – the original intention was to stratify the sample by ethnicity (as well as by gender, age, mental health diagnosis, and the person cared for). The extent to which this aim was achieved is not clear.

methods and evaluation

- Semi-structured interviews (with open-ended questions) and departures to pursue interesting themes. With follow-up interview 10 months later (with 28 families and professionals).
- Most interviews took place at the family home, except where mental illness precluded this.

key findings and conclusions

- Parents identified a range of reasons for their mental illness, or events that had contributed to it – past abuse, domestic violence, the death of a child or close adult, ill health from an early age, post-natal depression, family history, and marriage break-up.
- Co-morbidity was high, with only a quarter of the parents (11 of 40) having only one diagnosed mental health condition. Half the women had experienced domestic violence or other abuse, and most thought that was a major trigger for their illness.
- Parents (11 of 40), but not children, worried that

the children might inherit mental illness or assimilate learned behaviour.

- Discrimination from neighbours, friends, family, and professionals, was described by most parents (32 of 40).
- All the children were doing emotional caring tasks, and some nursing and practical tasks at times. The CPA service was described as satisfactory, but children provided the ‘consistent and continuous’ support that was needed.
- Parents identified one professional as their champion – not necessarily their key CPA worker, but someone they related to and who provided consistency and continuity. But professionals generally were not offering support to children and the wider family.
- Only 5 of the 40 children had been included in formal discussion with a statutory agency, and only 2 had received a formal assessment of need. The work of the Young Carer projects was valued – it filled gaps left by other agencies. At the first round of interviews 25 of the 40 children received support from the YC project only. The YC interventions were more likely than statutory agencies to take a family approach.
- Ignoring or excluding the views of parents and children misrepresents the context in which children assume care responsibilities at home and misses the diversity of experience, good as well as bad, of children’s lives.

A5

Stallard P, Norman P, Huline-Dickens S and Cribbe J
2002. Bath, England

mental health problems

Parental mental illness – depression(10), psychosis (6), affective disorder(5), eating disorder(1), chronic fatigue syndrome(1), borderline personality disorder (1).

what was studied

- The number of parents receiving help from the community mental health team who had children with depression.
- Parent and child views about the level of emotional and behavioural disturbance in the child.
- Parent and child views of the impact of parental mental illness on the child.
- The barriers between agencies that are associated with the study results.

sample and recruitment

A cross section of open adult cases was used.

- 24 adults (17 mothers and 7 fathers) attending the out-patient community mental health team. Half had had in-patient care previously.
- 26 of their children (10 girls and 16 boys, aged 6-17), from 16 families.

methods and evaluation

- Registrars conducted semi-structured interviews with parents and children about current illness, the child's understanding of that, and the effect on children's education, care, behaviour and relationships.
- The Strengths and Difficulties Questionnaire was completed by parents and children and the Birlerson Depression Inventory used to measure depression in children.

key findings and conclusions

- The children were concerned about their parents, had little understanding of their illness and often wanted more information. They wanted family relationships and practical things (money, housing, not being looked after) to improve. They worried most about their parent's health and about school.
- Parents viewed relationships with their children as positive. They were aware of the negative effects of their illness. They wanted children to have information, and to know they were not to blame, but they did not want them to be overloaded or burdened by their (parental) illness.
- The barriers to identifying children's needs were adult mental health approaches to family work, parental fear and denial and the wish to protect children, and children's fear and ambivalence.
- There was a need for more collaboration and integration of child and adult health services and a more family-centred focus to the work.

A6

Green R, Hyde E, Katz I, Mesie J, Vincenti O and Worthing D

1997. London Borough of Brent, England

mental health problems

17 of 18 parents had a formal diagnosis - manic depression (7), schizophrenia (5), depression (5).

what was studied

- Perceptions of children, parents, and professionals about the support families received, their views of mental health services, and changes wanted.

sample and recruitment

- Families with at least 1 parent with a mental illness diagnosis, broadly defined, and in contact with social services.
- Researcher was introduced to families by link professional after unsuccessful attempt to form sample through letters to families.
- Ethnicity – all from black and minority ethnic groups – African-Caribbean (11), white/Irish (3), Asian (2), African (1), mixed (1).

methods and evaluation

- A 2-year research and development project, researching family experiences, and developing policies, services and practice to help professionals work more effectively across agencies (to intervene early, preserve family integrity, support children, offer services without the need for child protection and court orders, draw on family strengths and respond to family culture, involve families in planning and evaluation).
- Workshops (for 44 professionals and 12 users) to discuss findings and to explore ways of involving families in policy and practice development.
- Interviews with 18 families (mothers, 2 male partners, 1 grandmother, and 10 children from 5 families) and 19 key professionals.

key findings and conclusions**mothers**

- Most were caring and protective of their children.
- Emigration, racism and childbirth were major stresses that contributed to their mental illness.
- Lack of a supportive partner, and poor quality of life, made things worse.
- Mothers were socially isolated; several had been abused when young; some had parents with mental health problems also.

children

- They were described by the researchers as 'loyal but fearful' – some more affected than others, some very anxious about their future.
- Almost half had been separated from both parents at some stage.

- Most took on some caring role at home.
 - They lacked information about parental mental illness, blamed themselves, thought it contagious, and felt embarrassment or guilt or loss.
- services**
- They were viewed negatively, because of fragmented delivery, a crisis focus with no follow-up once the crisis was resolved, no continuity and repeat assessments, and lack of information and counselling.
 - Only a child protection label guaranteed a service response, leading to a tendency to describe in those terms.
 - The human touch was valued most by parents – professionals who developed a trusting relationship, advocated, took risks on their behalf.
 - The greatest single difficulty may be the lack of co-ordination between adult and children's services.

A7

Sheppard M
1997. South England

mental health problems

Maternal depression

what was studied

- The rate of depression experienced by mothers subject to child care social work intervention, its relationship with their capacity to care for their children, its association with case status and social problems, and the extent to which social work intervention varied according to the presence or absence of depression.

sample and recruitment

- 116 of the 147 mothers on the care-managed caseloads of children and family social workers in 2 social services teams - one deprived urban, the other large rural.
- Invitations were issued by the family's social worker or team manager.
- Ethnicity – Researcher comments that there was a very small black population in sample area.

methods and evaluation

- Mothers completed the Beck Depression Inventory (BDI), a scale that measures severity of depression. Completed at home, during visit by researcher.
- Social workers scored mothers on the Deprivation Social Assessment Schedule (DESAS), within a week of the BDI, and without knowing the BDI result.

key findings and conclusions

- Only a third of mothers were not suffering some degree of psychological distress. A third were suffering clinical depression, including 13 per cent who were severely depressed.
- Families with a depressed mother had a greater number, range and severity of problems, and they were more likely to be categorised as more serious cases by social workers. Nearly all the mothers with severe depression fitted into the category of 'risk of physical or emotional harm'.
- The depressed mothers were deemed more frequently to have poorer social networks, to have problems with relatives and friends, to display more problems with parenting, and to have children with greater behavioural difficulties.
- Social workers were poor at identifying depression – they recorded it for 11% of mothers, compared with the BDI score of 36%. The interventions for depressed mothers did not differ in any marked respect from those for other mothers.
- Responding to depression is a social work task, but training is needed about the nature and impact of depression, and about effective management and therapeutic responses.

A 8

Davis L, Dibsall J, and Woodcock C
1997. London Borough of Bromley, England

mental health problems

Mostly depression, some receiving hospital care.

what was studied

- The needs of families, especially children, where a parent has a mental health, drug or alcohol problem. Plus parents' views of 35 local agencies.
- How to make earlier provision for children's needs, especially before serious concerns arise and when parents need hospital treatment.
- How to address the constraints on adult and child care teams that prevent a response to the needs of the family as a whole.

sample and recruitment

- 25 parents (22 women and 3 men) and 3 partners, and their 22 children (aged 5-17).
- 29 people who were working with the families.
- Families were recruited mainly through people who worked with them.
- Ethnicity - white UK.

methods and evaluation

- 78 interviews in total.
- Semi-structured interviews in family home, for 1-2 hours for adults and up to 1 hour for children.
- More informal interviews with agency staff.

key findings and conclusions

- Parents identified the main cause of their problems as partner difficulties, stress, life events, biological reasons, child care, their childhood, sadness, lack of support, money, work, housing.
- Children worried about their parent's illness and behaviour, and feared separation.
- Partners felt extreme emotional stress. They were exhausted and unsupported, had no-one to confide in, and were unwilling to ask for help for fear of being judged incompetent.
- An extra burden for parents was the unsuitability of hospital as a place for contact with children.
- Families were unaware of local agencies and what they provided. The services rated most helpful provided practical help and support – family aides, day nurseries, holiday play schemes, community psychiatric nurses, the CAB, counselling services.
- The quality and characteristics of helpers were the most important consideration for families. They valued respectful attitudes, good listening, confidence boosting, help to make decisions without taking control, regular contact and attention to all family members.
- The main recommendation was for a whole-family early intervention procedure.

A 9

Hugman R and Philips N
1992. North England

mental health problems

Formal psychiatric diagnosis.

what was studied

- Parents' mental health problems and experience of parenting, the link between the two, and the response of professionals.

sample and recruitment

- 24 parents (16 female and 8 male) who used mental health services, had a social worker, and volunteered for the study.
- Ethnicity - 23 white, 1 Asian.

methods and evaluation

- Interviews with open-ended questions, analysed by theme.

key findings and conclusions

- Mental health problems had had a negative impact on parent/child relationships but not all had sought professional help. They had adopted strategies to provide for children's safety and routines. When this failed they asked for help, but only as a last resort.
- Professionals focused on the child, not parental needs. There was an explicit focus on pathology, with risk to the child from mental health needs the focus of intervention. Parental strengths were rarely considered – their weaknesses were highlighted, and they felt judged as unable to parent well because of their mental health needs.
- Help was patchy unless their child needed help. Services did not take account of child care practicalities, and did not help parents explain their worries to others in the family.
- Parents wanted advice, advocacy and some involvement in services. They saw social workers as good sources of advice.
- Recommendations that social workers should attend to needs of all family and across whole life, and should recognise and work with strengths and capacities as well as needs. Service planning should acknowledge the fact that users are parents, should support this role, and should guard against the extremes of ignoring mental health needs or assuming that they inevitably put children at risk.

A10

Elliott A
1992. Leeds, England

mental health problems

Schizophrenia (4), manic depression (3), paranoid psychosis (1), nerves (1). Five had had in-patient treatment.

what was studied

- The experience of children, now adults, who had helped care for an ill parent. With particular focus on the support received and wanted, and the impact on their current life.

sample and recruitment

- 9 adult children (all but one female), now aged 22-41, who had cared for a parent when young. Of the 9 parents cared for, there were 5 mothers and 4 fathers.
- Recruitment was via the psychiatric day centre manager or the author or colleagues.
- Ethnicity – 6 white, 3 black or from other minority ethnic group.

methods and evaluation

- Interview (45-160 mins) at venue of choice.

key findings and conclusions

- As children, they lacked information about their parent's illness, and feared inheriting it. They found bizarre behaviour and suicide attempts hard to cope with.
- School attendance was not affected, but homework was hard to fit in. They had little help at home, apart from siblings and the other parent.
- All but 1 felt their adult life was affected – they were stronger, or less tolerant, or more appreciative; they had mental health problems that they attributed to their experience; they felt unsupported.
- What they would have wanted – greater understanding of what was happening, help with housework and the care of siblings, friendships, avoidance of periods in care, not to be used as interpreters, and specialist help and information about their parent's mental illness.

B1

Jones A, Jeyasingham D and Rajasoorihy S
2002. Manchester, England

mental health problems

Case examples indicate parental mental health problems (unspecified) in some families.

what was studied

- The extent and range of needs of black 'young carers', access to services by families, and how experiences are mediated simultaneously through race, gender, disability and class.
- The aim was to examine children's rights and disability, to contribute to a holistic approach to black 'young carers', and to make recommendations about service equity and adequacy.

sample and recruitment

- Recruitment was via the Black Young Carers Project run by the Bibini Centre, a service committed to holistic working with black children and families.
- Ethnicity – African Caribbean (15), South Asian (6), African (4), East Asian (3), Chinese (3), white UK (1).

methods and evaluation

- Interviews with 17 young people and 15 adults from 20 families (parents, grandparents, foster carer).
- A questionnaire survey of 40 agencies and discussions with 15 practitioners and managers.
- The young people helped devise the study questions and 3 were trained as peer researchers and did some of the interviews with young people.
- A dissemination event discussed agency proposals for follow-up action.

key findings and conclusions

- The contributions of children to family life were seen by parents as a major factor in keeping the family unit intact. Children and parents described benefits of caring, though some children felt a deep sense of dissatisfaction because of isolation, lack of choice and control, and the failure of professionals to give information and talk to them.
- Parents were best placed to decide the help children should provide. They did too much if services were inadequate or unhelpful because they ignored religion or culture or gender, or if parents feared family separation. The role of interpreters was sometimes inappropriate or created difficulties.
- The wider family was supportive but often unable or not expected to give regular or long-term help.
- Young people wanted services for their family's needs and their own needs.
- Religion was significant for most people and faith communities gave practical help. The local community was a potential source of support, especially when people had shared experiences of racism.

B2

Bibby A and Becker S
2000. Britain

mental health problems

Parental depression or manic depression (4), alcohol misuse (2), the rest were about parental physical health problems or the care of siblings, or unspecified problems.

what was studied

Children's experiences of being a 'young carer'.

sample and recruitment

30 'young carers' from over 100 projects were invited to send their views.

methods and evaluation

Young people described their experiences in their own words – as reports, stories and poems.

key findings and conclusions

- There are graphic descriptions of how depression feels (pages 56, 58, 64, 66).
- Policy and practice checklists are provided at the end of the report.

B3

Dearden C and Becker S
2000. UK

mental health problems

A third of the parents had mental health problems (unspecified), the rest had physical health problems, and a small proportion had both.

what was studied

- The transition of 'young carers' to adulthood and the factors associated with care responsibilities that affect those transitions. Topics covered included family structure, the nature of parental illness, education, income, housing, leaving home and separations, becoming adult, and services.

sample and recruitment

- 60 'young carers' – 36 were aged 16–18 (two-thirds female) and 24 were aged 19–25 (almost all female).
- Recruitment was via support projects and 500 letters distributed with a questionnaire.
- Ethnicity - 4 from Black or minority ethnic groups.

methods and evaluation

- Semi-structured interviews, at home or a venue of choice, and lasting up to 2 hours, were conducted with current or recent past 'young carers'.

key findings and conclusions

- The prevalence of mental health problems (a third, including alcohol or drug misuse) is similar to that found in national surveys.
- The emotional support provided is higher when parents have mental health problems. Other impacts relate to family income, the nature of the illness, family structure and availability of services.
- It is difficult for young people to gain independence if provision is not made for their parent's independence.

B4

Shah R and Hatton C

1999. UK

mental health problems

Of 8 mothers, 5 had depression and 3 a psychotic illness.

Of 4 fathers, 2 had a psychotic illness, 1 had depression, and 1 had a head injury.

Of 2 grandparents, 1 had dementia.

Other parents and relatives had depression, manic depression and schizophrenia.

what was studied

- Perceptions of South Asian 'young carers' and their role and its impact on themselves, what helps them cope, the support available, cultural expectations about caring for relatives, information about services, and messages for practice.
- The study was the first with 'young carers' from minority ethnic communities. It was important because of the disadvantage experienced by group members, the myths about black and minority ethnic people living in the extended family system, and the development hitherto of definitions, research projects and practice guidelines with an exclusive focus on white 'young carers'.

sample and recruitment

- 19 'young carers' (11 girls and 8 boys) aged 8–20, living in 13 households and caring for 14 older-generation relatives. 3 parents withheld consent, so those under 16 became excluded from the sample.
- Recruitment was via 2 Barnardo's projects. One project received a substantial number of referrals from specialist adult mental health services so may have resulted in an over-representation of parental mental health problems in the sample.
- Ethnicity – predominantly South Asian, with wide diversity, including Indian, Pakistani, Malawi, Zambian, East African Asian. Religion - half Islamic and half Hindu.

methods and evaluation

- Semi-structured interviews, at home, lasting up to 90 minutes.
- Focus groups and an advisory group checked researcher interpretations of findings.

key findings and conclusions

- The changes in behaviour displayed by parents with mental health problems can be traumatic, especially for younger children. There were loving relationships between children and those they cared for, reinforced by stigma and racism.
- Young people providing care developed sensitivity but also experienced disruption in their social life, education and plans for their future. For a minority,

the experience led to psychological distress that required help from mental health services.

- Young people felt isolated. This was reinforced by stigma and racism, and sometimes by negative attitudes from family members who took the view that children should provide care for their parents.
- The experiences feel similar to those of white 'young carers' although there may be differences in family attitudes to providing care and seeking help, and in the willingness of services to help. Services lacked sensitivity, displayed stereotypical views about culture, and were often not available. There was a lack of information for, and consultation with, 'young carers' despite the expectation that they would provide care.

B5

Strathclyde Centre for Disability Research, and Centre for the Child and Society
1999. Glasgow, Scotland

mental health problems

Depression and manic depression (3), alcohol misuse (3), drug misuse (2), schizophrenia (1), agoraphobia (1), post-traumatic stress disorder (1).

what was studied

The needs of 'young carers', the positive and negative effects of providing care, and ideas about present and future services.

sample and recruitment

- A door-to-door survey of those caring for an adult known to the social work department and an interview with 20 of these families.
- A school survey (including primary feeder classes) of 117 of the 507 pupils who said they had care responsibilities at home.
- 20 of the children cared for a parent, including 3 with depression 3 with alcohol misuse problems.

methods and evaluation

- Direct contact with young people identified via local projects - interviews with 14 White Scottish young people (9 girls and 5 boys) from 10 families, and focus groups with 12 young people aged 8–15 (half girls, half boys). 11 had a disabled parent – including 3 fathers with mental health problems and 2 with drug misuse.
- The school survey included the Rosenberg Self-Esteem Scale, the global depression scale, and questions about self-concept, perceptions of health, and overall quality of life.
- A comparison group consisted of young people who were not 'young carers' – 12 young people aged 9–16 (11 girls and 1 boy).
- Ethnicity – White Scottish.

key findings and conclusions

- It was hard to include parental mental health in the study, despite special attempts to do so. The majority of parents had physical health problems.
- Children identified in the school survey as 'young carers' were more depressed than other children, had lower self-esteem, were less happy with themselves and their life, and more likely to be bullied.
- Services needed include awareness raising, extra help for the child, more public knowledge about services, easier access to services, and a whole-family response to needs.

B6

Centre for the Child and Society, and Strathclyde Centre for Disability Research
1999. Renfrewshire, Scotland

mental health problems

12 families included a disabled parent and in 4 of those families the parental disability was a mental health problem (unspecified).

what was studied

- Estimated numbers of families with disability, evidence from the literature, and the views of service providers, parents and children. The study was intended to include all types of disability, affecting both children and parents, but the reported findings related mainly to children with disability, with very little information about parental mental health problems.

sample and recruitment

- Recruitment of service providers (18) was via recommendations of the Council, plus personal contacts.
- Families were identified via schools (58 families) and social services (10 families).

methods and evaluation

- Analysis of a postal questionnaire returned by 68 out of 300 households targeted because a parent was registered disabled or a child had special needs.
- Semi-structured interviews (at the family home and lasting 30 minutes) with 21 children (from 11 families).

key findings and conclusions

- It was hard to include parental mental health in the study – only 4 families were identified via the questionnaire, and contact could not be made with any of the 5 children identified via education or social services.
- The stress and difficulties experienced do not stem solely from disability – the wider context is also relevant: transport, work opportunities and social attitudes.
- Across the wide range of families there is a need for better services and service information, and an approach that considers the whole family and is holistic, including recreation and education as well as care services.
- There is a need for individual and group support for carers and those cared for, increased disability awareness by teachers and other professionals, and public education to dispel ignorance and prejudice.

B7

Frank J, Tatum C and Tucker S
1998. Hampshire, and all England

mental health problems

Half of those interviewed had cared for someone with a mental illness, including schizophrenia, severe depression, and alcohol misuse.

what was studied

- How care responsibilities had shaped the perceptions, outlook and attitudes of former 'young carers'; whether these had had a psychological impact on their life; whether they had led to long-term exclusion or discrimination from agencies, relatives and peers; and lessons for practice.

sample and recruitment

- Local recruitment (Hampshire) via adverts in community publications and contacts in the carer network, and national recruitment via the Carers National Association (CNA).

methods and evaluation

- 35 semi-structured interviews, lasting up to 2 hours – mainly at home but some by phone – with local people.
- 41 postal questionnaires that had been distributed with the CNA newsletter.

key findings and conclusions

- Where mental illness had featured, an extra layer of experiences supported and maintained a conspiracy of silence. Feelings of shame and embarrassment meant that the world was kept at arm's length, with people fearful of being made fun of because they were not like other children.
- Children felt that their parents did not want others to know their circumstances, and that services were slow to respond when help was requested.
- A psychological impact on children was more likely in cases of parental mental health needs. Half the former 'young carers' had had, or planned to have, contact with a counselling service.

B8

Walker A
1996. Britain

mental health problems

All had physical health problems but, for 2, the main problem was anxiety and depression.

what was studied

- The extent of caring nationally and the nature of caring arrangements in families, including the health problems, external help, financial help, and attitudes to the role of those caring and those cared for.

sample and recruitment

- This was a general population sample of 12,000 households (as part of an OPCS survey) in order to determine the number of 'young carers'.
- 7 households (including 18 'young carers') met Department of Health criteria for 'young carer', suggesting a national figure of between 19,000 and 51,000.

methods and evaluation

- Interviews were held with 14 household groups, plus separate interviews with the young person doing the caring (11) and the disabled person.

key findings and conclusions

- The 2 mothers with anxiety and depression needed help to get out of the home (as did most of the other parents being cared for).
- No other comments related specifically to parental mental health problems.

B9

Newton B and Becker S
1996. London Borough of Southwark, England

mental health problems

Depression (4), unspecified mental illness (1) and learning disability (1) – in addition to physical disability or illness.

what was studied

- The experiences and needs of ‘young carers’ and implications for policy and practice.

sample and methods

- Semi-structured Interviews with 12 children (11 girls and 1 boy) aged 9–17, from 11 families, and mostly caring for their mother.
- It took 70 letters and 210 phone calls to identify 27 children who might be interviewed.
- Ethnicity – 5 children from a black or minority ethnic group.

key findings and conclusions

- The emotional consequences of caring limited the children’s social life and friendships and over half had missed school.
- Where parents had mental health problems the children had the greatest fear of becoming known to statutory services. They felt stigma by virtue of their association with their parent.
- Needs clustered into 3 areas – for information, for someone to talk to, and for practical services.
- In providing sensitive services, children should not be used as interpreters.

B10

Frank J
1995. Hampshire, England

mental health problems

Not specified.

what was studied

- The number of ‘young carers’ and their major needs, a model for monitoring their needs, and practice guidelines for social workers.

sample and recruitment

- Children caring for a parent with a long-term disability or illness.
- Of the 70 families identified, 19 parents (16 with a sole child) had a mental health problem and 8 had alcohol or drug misuse problems.
- Recruitment was via schools, health and social service staff and voluntary sector groups.

methods and evaluation

- Home interviews with 16 ‘young carers’, plus contact with some former carers.

key findings and conclusions

- It proved difficult to get information from agencies about families with mental health or substance misuse problems. Re mental health problems, key workers thought parents would refuse consent and that questions about the child’s care might affect the parent’s mental health and the family’s stability. Re substance misuse problems, workers thought parents would be fearful of acknowledging their problems, of having their child removed, of losing the service.
- The information received revealed that many children were looking after siblings, ensuring their parent’s safety, reminding them to take medication, and coping with their unpredictable behaviour patterns.

B11

Dearden C and Becker S
1995. Britain

mental health problems

- 23 per cent of the sample had mental health problems (depression, manic depression, schizophrenia, substance misuse, some unspecified).
- 15 per cent had alcohol or drug misuse problems or learning disabilities (some unspecified).

what was studied

- Data about a large number of 'young carers' and a comparison of findings with data from smaller studies, to identify emerging patterns about the age, gender, ethnicity and caring responsibilities of 'young carers'.
- Children's views about whether projects affected their life and were helpful.
- Staff views about what influences the provision of services.

sample and recruitment

- 26 projects (of 37 invited to participate) provided statistics about 641 children (under 19 years) using their services.
- Ethnicity – 90 per cent white.

methods and evaluation

- Analysis of statistical data provided by projects and some interviews with staff.
- Interviews with 8 'young carers' – 5 were caring for a parent with mental health problems.

key findings and conclusions

- Most of the children lived with a lone parent (60 per cent at a time when the national average was 19 per cent) and a fifth of the children had no support except from the 'young carer' project.
- There were particular features where parents had mental health rather than physical problems – the children were less likely to provide intimate care (9 per cent v 29 per cent) and more likely to provide emotional support (43 per cent v 21 per cent). Where parents had a learning disability, the children were more likely to be caring for siblings and less likely to be providing emotional support to parents.
- Children from black and minority ethnic groups were more likely than others to be caring for a non-parent or sibling and to be providing intimate care.

B12

Dearden C and Becker S
1995. Nottingham, England

mental health problems

- 8 parents (12 per cent of the sample) had a mental illness and alcohol or drug misuse problems.
- 7 parents (11 per cent) had a specific learning disability.
- The rest had mainly physical health problems.

what was studied

- The services provided for a two-year period by Crossroads, a 'young carers' project, and the value families attached to them.

sample and recruitment

- Children and parents using the service

methods and evaluation

- Interviews with children and parents (almost all mothers) using the service and phone contact with professionals who referred families.
- Findings were compared with data collected from national 'young carer' projects.

key findings and conclusions

- Parents, children and professionals were happy with the opportunities provided for children.

C1

Mutter R, Judge N, Flynn L and Hennessey J
2002. Essex, England

mental health problems

Severe and enduring mental illness requiring a Care Programme Approach (CPA) – including personality disorder (5), bipolar (4), depression (3), schizophrenia (2), psychosis (1) and Aspergers syndrome (1).

what was studied

- Whether the Family Group Conference (FGC) model of planning could increase support, challenge isolation and combat discrimination. It was developed because a large proportion of the children referred to the Children and Families FGC project lived in families where mental health, and substance misuse, were key features.
- Whether the model could be transferred to a new area (adult mental health), how the model was operating, and participants' views about process and outcomes.

sample and recruitment

- 16 cases using an FGC (it is unclear how many were adults with a dependent child).
- Anyone receiving CPA could be referred.
- Ethnicity - white UK (the researchers comment that 2 per cent of adults getting CPA help in Essex are from black and minority ethnic groups).

methods and evaluation

- The University of East Anglia evaluated the project over 2 years.
- Quantitative and qualitative data from each conference was collected and analysed.
- 39 interviews were held overall – with 4 users, 13 relatives, 2 friends, and 11 professionals.

key findings and conclusions

- Carers and relatives engaged with the programme even when the user had previously experienced long-term disengagement from services.
- Acute in-patient admissions were avoided because services were accessed early and support was provided by agencies and families.
- Satisfaction and confidence with the process were reported. Bringing families together increases support at times of crisis, and families can contribute to finding solutions.
- FGCs reinforce good practice.
- The model was deemed to be the most effective approach in mental health work because people are listened to, anxiety is reduced, trust can develop, family communication helps make explicit the things that are often kept implicit, information reduces anxiety and increases choice and control and attention to needs.

C2

Place M, Reynolds J, Cousins A and O'Neill S
2002. Northern England

mental health problems

Mainly moderate depression, but over half had other problems too – agoraphobia (5), personality disorder (4), eating disorder (2).

what was studied

- The effectiveness of 'Strength to Strength' – a 6-month resilience programme for the children of adults with depression, to promote positive mental health in vulnerable children. Depression was chosen because of the known risk of up to 40 per cent of children developing their own mental health problems, and because of effective USA interventions (see D4).

sample and recruitment

- Children of 20 depressed parents needing support from a mental health worker.
- Children aged 7-14 (to keep the intervention elements relatively uniform).
- Children who did not need own referral to CAMHS (to maintain a focus on promoting resilience rather than responding to specific problems).
- Referral by family or professionals.

methods and evaluation

- The service aims to boost individual, family and community protective factors. An initial assessment of these is shared with the family. There are 2 full-time workers, with nursing and social work backgrounds.
- The intervention package has 3 elements:
 - 1) education about depression, including false beliefs
 - 2) 10 child and family sessions about family dynamics and interactions, to focus on family strengths rather than illness
 - 3) 8 weeks of skill development for children, via activities in community
- Scales were used to measure the strength of children's protective factors and their ability to participate and reflect – Self-Description Questionnaire (child), self-competency section of Achenbach Child Behaviour Checklist (child), SDQ (parents), and Family Adaptability and Cohesion Evaluation Scales (FACES).

key findings and conclusions

- (After service running for 9 months, with 10 completed cases and 10 almost completed)
- Almost all parents had low self-esteem. But families often had strengths too – three quarters displayed tangible warmth when speaking of their child, and half had a good local network, with neighbours and others.

- Parental fears that discussion of mental health would impact negatively on their child were not borne out.
- The programmes increased social activity, reduced emotionality, and helped families become more flexible. Families moved towards a more balanced pattern of interaction, and children gained in social functioning and involvement in activities.
- There was a wide range of complex problems, and parents with these co-morbid psychiatric symptoms (including difficulties deemed intractable – like personality disorder and substance misuse) were able to take part in the programme, despite the intention to focus on parents with depression.
- It is possible to set up a prevention project, modelled on earlier research findings and evaluated programmes, despite the general focus (in the UK) on services that respond to problems.

C3

Simons J, Reynolds J and Morison L
2001. London, England

mental health problems

Half of the mothers identified as in need of help with relationship problems were also identified as having post-natal depression.

what was studied

- The effectiveness of a training course in extending the ability of primary care workers to identify and respond to relationship problems of mothers and partners during the post-natal period.

sample and recruitment

- All new mothers (approx 1,000) in health visitor clinics.

methods and evaluation

- A randomised control trial, with health visitors in 9 'intervention' clinics, trained to ask about and help with relationship problems, matched with 9 'control' clinics where health visitors expected to rely on problems being revealed spontaneously.
- At the post-natal 6-8 week developmental check mothers were invited to complete a screening scale for relationship problems and, if needed, offered help (supportive listening, advice or referral).
- At the 12-week follow-up all mothers completed a self-report questionnaire, and 25 of the mothers who had been offered support were interviewed.
- Health visitors in the intervention clinics completed a questionnaire.

key findings and conclusions

- Mothers attending the intervention clinics were 4 times more likely than others to reveal relationship problems, and 6 times more likely to be offered help.
- These mothers were twice as likely to report having discussed relationship problems with their health visitor, and 75 per cent more likely to have received help.
- The formal screening seemed effective in increasing the detection of depression and other emotional distress, with more mothers in the intervention clinics offered help with post-natal depression also.
- After a short (4-day) course, health visitors could become effective providers of screening and support to help parents find ways of dealing with their problems. The help was usually welcomed by mothers, and the course highly valued by the health visitors.

C4

Barlow J, Coren E and Stewart-Brown S
2001. Oxford, England

mental health problems

Mainly depression and anxiety.

what was studied

- The effectiveness of group-based parenting programmes in improving maternal psychosocial health, including anxiety, depression and low self-esteem.

sample and recruitment

- 23 studies, identified from a wide range of electronic databases, the Cochrane Library, and the National Research Register. 17 studies gave sufficient data to calculate the effect size of the intervention.
- Studies had to include at least one group-based parenting programme, with participants randomly allocated to an experimental or control group, and at least one standardised instrument to measure maternal psychosocial health.
- Programmes used a range of techniques – behavioural, cognitive-behavioural, multi-modal, humanistic, and rational emotive therapy.
- Ethnicity – mainly white, from the UK, USA, Ireland, Canada and Australia.

methods and evaluation

A systematic review of the 23 studies

key findings and conclusions

- There were significant short-term improvements on 4 key outcomes – depression, anxiety, self-esteem, relationship with partner.
- There was no evidence of effectiveness for the fifth outcome – social support – possibly because the outcome instruments used were not designed to measure this type of change.
- At follow-up (up to a year later) there was continuing improvement in self-esteem, depression and relationships.
- It was not possible to show which groups of parents are likely to benefit most, as there was insufficient attention at the outset to identify the severity of maternal problems.
- Results are positive overall, with programmes having a potential role to play in promoting maternal mental health and having a likely indirect impact on children's mental health.
- More longer-term follow-up is needed, as is attention to which factors (eg. quality of delivery) make a difference in parents' perceptions of the value of programmes. The results should not be generalised to fathers, or to black and minority ethnic mothers, given the sample composition.

C5

Rhodes H and Hall A
2001. London Borough of Lewisham

mental health problems

Mainly severe depression, also schizophrenia, anxiety, personality disorder, and dual diagnosis, including learning disability.

what was studied

- Building Bridges, a whole-family service for parents with enduring mental health needs and dependent children. Tested against objectives: (1) providing tailored help re relationships and likelihood of neglect, harm, local authority care, via family work, group work and training, (2) reducing emergency use of psychiatric hospital care and providing safe visiting, (3) improving joint work by child care and adult mental health professionals.

sample and recruitment

- 19 mothers from 110 referrals in years 2 and 3.
- 20 children (7 girls and 13 boys, aged 5+) from 10 families.
- 20 referring professionals.
- Recruited via contact with families.
- Ethnicity – referrals reflect local area: over a third white, a fifth black Caribbean, the rest mixed parentage, black African, Indian, Turkish, other. Sample unspecified, but cases indicate at least a third black Caribbean.

methods and evaluation

- Interviews with parents and children, generally at family home.
- Brief phone questionnaire with professionals.

key findings and conclusions

- Families deprived and socially excluded - major upheaval, dislocation, loss, abuse when young.
- Most linked onset of depression to recent specific incident, especially death, birth, relationship problems.
- Most children worried about their ill parent; valued family activities and talking to workers.
- Parents very satisfied with the service, especially home-based help, family activities, counselling for children, and worker commitment.
- Professionals valued most the practical and emotional support for families, the trust engendered by workers, improvements in school attendance and parents' management of children.
- Volunteer befrienders and learning/literacy support workers offered flexible, non-professional help. Staff positively encouraged contact after formal service ended, via phone calls and cards.

C 6

Davis H and Spurr P

1998. London Borough of Lewisham, England

mental health problems

Almost half the mothers had suffered significant depression since the birth of a child. Others experienced mood swings and anxiety, or were very isolated, or had been abused as a child, or had learning disability.

what was studied

- The effectiveness of a family support programme (rather than a focus on the child's behaviour) to help put parents in control, understand their difficulties, and devise and implement a plan to achieve goals they set for themselves.
- The feasibility of setting up this community service – integrated with routine services – in a highly deprived, inner-city area.

sample and recruitment

- 87 families, with psychosocial problems in pre-school child, emotional problems in parents, relationship difficulties, other stressors.
- Most referrals from health visitors and families themselves, others from GPs and nursery schools.
- Ethnicity – reflects local area: half white UK, the rest black Caribbean, black African, mixed race, Asian.

methods and evaluation

- Families had weekly sessions, usually at home, for about an hour, with a Parent Adviser. Advisers had training – half a day for 15 weeks – in counselling, parenting, child behaviour management, and a collaborative style of working with parents.
- Outcomes for families were tested using 8 standardised scales before intervention and 4 months later, with a comparison group of 38 families receiving normal local services. Questionnaires were used to gauge family and referrer satisfaction.
- The trained Parent Advisers were tested for gains in knowledge, skills and attitudes.

key findings and conclusions

- At 4 month follow-up there was a significant reduction in parental anxiety and depression, stress, and the severity of problems and distress caused by them, and increased self-esteem and more positive feelings and responsiveness towards their child, plus improved child behaviour. In two-thirds of the cases closed at 4 months, problems had been largely or completely resolved. Parents and referrers were very satisfied with the service.
- Many families responded in a relatively short period, but it was important to retain the flexibility to offer long-term support when needed.

- Some families with multiple and complex problems, as well as those with lower-level needs, responded well to this type of service.
- There were no improvements in couple relationships or social isolation – specific interventions may be required for such needs.
- Parent Advisers found it hard to resist trying to solve problems for families, especially those with a medical background, but most succeeded. The training can be applied to non-professional as well as professional people, and enables family ethnicity and culture to be taken into account. A European study of the training method is being analysed. Preliminary findings indicate that the training is highly acceptable and beneficial to primary health care workers, and has increased significantly the accuracy of their identification of family risk factors. There is evidence for the service being more valued by mothers than standard services. Despite problems in maintaining the anticipated intensity of the intervention, there is some evidence of predated outcomes being achieved in some countries at two-year follow-up (personal correspondence with main author, April 2004).

C7

White C, Agnew J and Verduyn C
1998. Salford, England

mental health problems

Parents in the community, many with undiagnosed depression.

what was studied

- Whether a community-based early intervention service would succeed in providing effective services to a high-risk population in an area where services were hard to reach.

sample and recruitment

- Parents of pre-school children in an area of high socio-economic deprivation.
- An assertive outreach approach was used to engage families.

methods and evaluation

- This was a pilot study (later granted mainstream funding, and beyond the pilot area).
- The service included parenting groups using Webster-Stratton techniques; clinic sessions in community venues; and consultancy, training and support for Tier 1 professionals.
- For the parenting groups, evaluation included satisfaction ratings and standardised scales to measure change. Scales for adults – the Beck Depression Inventory and the Rosenberg Self-Esteem Inventory. The 5 scales for children included the Child Behaviour Checklist.
- Scales were completed (by those receiving the pilot service) pre- and post-intervention, and at 6 and 12 months follow-up. The comparison group were scored at 6 month follow-up.

key findings and conclusions

- The parenting groups reduced the parental rating of their child's problem behaviour and had a positive impact on parental depression and self-esteem, with change sustained at follow-up, and better results than in the control group. Delivering the service from the community nursery was deemed helpful in reducing stigma.
- Telephone contact with families, rather than the traditional letter of appointment, worked well. So did personal encouragement when children needed a more specialist hospital service – 90% of families took up the referral made for them.
- The training for professionals increased their understanding of parent and child needs and of behaviour management interventions, boosted confidence to deal with problems, and increased referrals to the service. The supervision provided for primary health care professionals was deemed friendly and useful.

D1

Orel NA, Groves PA and Shannon L
2002. Ohio, USA

mental health problems

Major depression, bipolar disorder, schizophrenia.

what was studied

- Positive Connections (Big Brother Big Sister) – an intervention programme for children of parents diagnosed with a mental disorder. The programme stresses good collaboration with mental health agencies to match children to a high-quality adult mentor.
- The programme's main purpose is to enhance the child's ability to understand and cope with parental mental illness by providing education, support and mentoring. Long-term aims are to (1) increase the child's awareness and understanding of mental illness, (2) enable the child to identify and cope with their feelings about parental mental illness, (3) strengthen the child's support system.

sample and recruitment

- 11 children (8 girls and 3 boys) aged 8-13 years; 8 lived with their mother, 1 with their father, 1 with a grandparent, and 1 was in foster care.
- The children have low-level needs (anger, fear, sadness, confusion, isolation, guilt, embarrassment) but do not need a specialist service.
- 7 children had previously had mental health problems of their own (overdose, post-traumatic stress disorder, major depression, attention disorder).
- Ethnicity – 9 white, 2 bi-racial, 1 African American, 1 Hispanic.

methods and evaluation

- Pre- and post-test scales used – the Self-Esteem Index and the Family Assessment Measure (family functioning on tasks, role performance, communication, affective expression, involvement, control, values and norms).
- Questionnaires recorded parents' views of the programme and of their child's self-confidence, social competence and caring ability.
- The views of mentors and professionals.

key findings and conclusions

- Increased children's self-esteem and family functioning; but less of an increase in feelings of personal safety.
- All the children could describe their parents' crisis management plan and identify local support. Most accurately described mental illness, explained that their parent had an illness rather than just being out of control, and knew they were not responsible. The scales needed to be changed after this pilot project because the data was hard to interpret.

D2

Langrock AM, Compas BE, Keller G, Merchant J and Copeland ME
2002. Vermont, USA

mental health problems

Major depressive disorder, experienced currently or since the birth of a child.

what was studied

- The stressful situations children experienced, how children coped and responded, and the role of coping as a mediator between stress and children's emotional and behavioural problems.
- It was hypothesised that children of depressed parents live in stressful home environments characterised by marital conflict and parental behaviour that is intrusive and withdrawn, and that there is an association between frequent exposure to parental stressors and children's behaviour.
- 3 types of coping were studied – (1) direct action to change one's situation or emotions, (2) fitting in or adapting to one's situation, (3) disengaging, to distance oneself from a painful situation.

sample and recruitment

- 66 clinically depressed adults (56 mothers and 10 fathers) and their 101 children aged 7-17.
- All were part of a longitudinal study assessing the acceptability and feasibility of an educational intervention programme for families coping with parental depression (but the information relates to the period prior to their involvement in the study).
- Recruitment via professionals and public adverts.
- Ethnicity – 98 per cent white (reflects local area).

methods and evaluation

- A postal questionnaire was returned by 66 of the 70 parents identified for the study. Paid \$30.

key findings and conclusions

- Children of depressed parents have higher rates of internalising and externalising emotional and behavioural problems when compared with children in the general population, are exposed to parental behaviour that varies from intrusive to withdrawn, and use a variety of coping strategies. The children have higher rates of anxiety/depression and aggression than the norm.
- The way children cope affects the way they feel and behave – those who use strategies to accept or adapt to the stress of parental depression have fewer adjustment problems than those who were unable to shift their focus from parental problems.
- (Unlike in other studies), the researchers did not find that exposure to marital conflict was linked to greater anxiety or aggression in the children.

D3

Bond LA
1999. Vermont, USA

mental health problems

Poor and severely isolated mothers.

what was studied

- Progress of mothers in a programme of group dialogue and activities, including problem solving and support.

sample and recruitment

- 60 women – poor, rural, under-educated mothers in a socially and geographically isolated area, with the State's highest levels of unemployment, substance misuse and domestic violence.
- The women felt powerless and voiceless, lacking control over their destiny, family and community. They had had little opportunity to identify, explore and express feelings, and their lives were marked by a lack of mutual, reciprocal relationships.
- They were recruited via local sources – the criteria included a pre-school child, poverty, little family support, plus risk for child of abuse/neglect or risk for mother because of unusual stress or isolation.

methods and evaluation

- Mothers met in groups of 8-10, for 3 hours weekly over 8 months, in a familiar place (church, school, family centre), with professionals who offered encouragement and guided activities.
- The focus was on dialogue and narrative activities – they taped one another and fed back the words for reflection and revision. They then used the same technique with their children and partners, plus group exercises in problem solving and helping.
- Quantitative data was collected before and after the programme and 10 months later. 60 controls completed the same assessments but had no intervention.

key findings and conclusions

- The women gained in knowledge (compared with the control group), with the gap more marked at the 10 month follow-up. The women developed skills and tools to improve their environment for themselves and others, fostering dialogue and cognitive growth. They had created significantly greater social support systems for themselves.
- The interviews revealed changes in the women's self-image, self-esteem, social support, goals and skills. They valued themselves as individuals with ideas, feelings and vision. They saw themselves as more active and skilled in family, friendship and community life. They became more able to think through opportunities and conflicts and saw themselves as active agents, with the power to make important changes in their life.

D4

Beardslee WR, Salt P, Versage EM, Gladstone TRG, Wright EJ and Rothberg PC
2000. Boston, USA

mental health problems

Depression and manic depression.

what was studied

- A short-term family intervention (PIP – Parents in Partnership) intended to provide families with cognitive information about the symptoms of depression and the characteristics of risk and resilience in children. It grew out of a public health model that stressed the importance of increasing public awareness of depression. The scheme was introduced as a trial of a service that was short term, family based and psycho-educational.
- The intervention is family-based because of knowledge that families manifest both risk and protective factors in the lives of children. The structure of the intervention helps parents focus on the multiple pathways to health or vulnerability in their children.
- Parents have 6-10 sessions with a clinician, to evaluate risk and resilience characteristics in their own children, and to prepare them for holding a family meeting. The goal of the meeting is for parents and children to increase their knowledge and to discuss their experiences of affective illness.

sample and recruitment

- 37 families, with a child aged 8-15, and at least one parent with a recent episode of affective disorder. Almost all parents were involved in mental health therapy (92 per cent) and medication treatment (89 per cent).
- 19 of the families received the pilot service (weekly sessions for parents and children by a clinician, and a linking of information about depression to the family's experiences) and 18 received the 'normal' service (2 lectures on depression, for parents only).
- Recruitment was from a large health maintenance organisation in the area.
- Ethnicity – predominantly white, middle-class.

methods and evaluation

- Family members (children and parents) were interviewed, and also completed standardised scales to measure depression (the Beck Depression Inventory), the impact of the parental disorder, parental concerns, and change in behaviour and attitudes. Tests were conducted before and after the intervention and about 18 months later.

key findings and conclusions

- The programme prevents emotional pain from becoming psychological pathology in the child or

parent because inviting and acknowledging their emotional reactions helps prevent this emotion from being blocked off by family members.

- The structure of PIP provides overt permission and a safe context for family members to tell one another about the emotionally painful experience of depression. The programme helps parents to tell their children that they are not to blame for their parent's depression, to explain why parents cannot be available for children during periods of depression, and to provide for someone else to be available at those times.
- Children learn that they do not have to use energy avoiding thinking about painful emotions – they learn that they can move beyond anger, survive each others' anger, and not be the go-between between parents. They can go their own way, without feeling overly responsible or loyal.
- There are lessons for daily practice with families – there is value in enabling children and parents to meet together, in providing periodic long-term follow-up with children and parents, in making individual therapy available for children who need it, and for providing help to parents through therapy and community resources.
- Both programmes achieved positive gains but the one facilitated by clinicians – and involving the children – was associated with greater gains than the lecture programme for parents.

D5

Garley D, Gallop R, Johnston N and Pipitone J
1997. Toronto, Canada

mental health problems

Mood disorder (depression).

what was studied

Children's perceptions of depression, how they coped when their parent was ill, their concerns, the changes in their life, and the help that other families might want.

sample and recruitment

- Six children (3 boys and 3 girls) aged 11-15, with a parent assessed or treated for mood disorder through the out-patient clinic of the psychiatric facility linked to the University.
- The children were living with or in regular contact with their mentally-ill parent (2 mothers and 4 fathers). In all but one family the parents were separated or separating.
- The children had no problems of their own (behaviour, substance misuse or mental health problems).

methods and evaluation

- The children attended 4 group meetings, for an hour each week. A fifth meeting was planned, but not needed.
- The groups were run by a clinical nurse specialist and the head of child care, both experienced in adolescent and family work.
- The meeting was semi-structured and videotaped.

key findings and conclusions

- The children's greatest worry was that their parents had separated, or might do so. Other concerns were the impact on school life of a parent with mental illness, and fear of developing the illness themselves.
- The children wanted information about the illness (some had researched this on their own) and they found it helpful to understand the signs that meant the illness was on its way.
- They welcomed their parent's occasional hospital stays – relieved to be cared for by other relatives.
- Children and parents tried to protect one another but some children had a heavy burden. They coped by being with friends or keeping active.
- They valued the chance to talk in a group (it helped them feel normal) and thought their parents would welcome something similar.
- The researchers recommend self-help groups for individuals and families, and psycho-educational groups, run by hospital nurses, to provide safe and specialist time – to learn about mental illness and share concerns without stigma or fear of reprisal.

D6

Lier L
1992. Denmark

mental health problems

A range of major disorders – personality disorder, psychosis, schizophrenia, mood disorder.

what was studied

- The first 5 years of a programme offering care to newborns and their mothers, from a new infant psychiatric Unit based in a hospital.
- The main principles of the service were early identification of mothers, early assessment of parental ability and children's vulnerability, continuity of contact with a minimal number of professionals, and co-ordination across disciplines (primary health, obstetrics, social welfare, and adult and infant psychiatry).

sample and recruitment

- All new mothers with mental illness.

methods and evaluation

- The Unit collaborated with hospitals and services across Copenhagen.
- Services included mother and baby groups, help at home about child development, short-term relationship therapy in a day clinic, individual therapy for mothers' mental health problems, support for social problems, support for fathers who were main carers, supervision of day care and foster care placements, and cognitive therapy programmes for mothers with schizophrenia.
- Mother/child attachment was assessed after 12 months, and the child's cognitive development assessed at age 3.

key findings and conclusions

- Most mothers accepted referral to the Unit, child difficulties were caught earlier than previously, and complications were reduced.
- Providing care and treatment to mothers with mental illness, and their babies, works if the underlying assumption is that mothers will cooperate, and if they have continuity of contact from a familiar professional.

references - grouped

These have been grouped as follows:

- A-D the impact and intervention studies used for the review
- E other reports of single studies
- F literature and research reviews or overviews
- G government law, policy and guidance
- H local practice experience
- J training and other resources

Within each group the references have a consecutive number, used in the main body of the review. References that could fit under more than one category have been allocated to the one that reflects their major content.

A impact studies – mental health

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Parental Mental Health and Child Welfare Network. The Network is for social care and health workers who work with parents with a mental health problem or their children. Its aim is to promote joint working between adult mental health and children's services. You can submit practice examples and key messages from your own research, to help inform a forthcoming Knowledge Review and then guidance about joint working arrangements. Make contact via the Social Care Institute for Excellence (SCIE) website: <http://www.scie.org.uk/mhnetwork/index.asp> H16

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common mental health words and phrases

Most of the following definitions are taken from the National Service Framework for Mental Health (G3), the Guide for Refugee and Asylum Seekers Advisory Workers (J4), YoungMinds publications (J5), leaflets from the Royal College of Psychiatrists (J6), material from Richmond Fellowship Training and Consultancy Services (J7), and publications about Community-Oriented Primary Care (J8).

common mental health problems

This term is used in current government guidance, including the National Service Framework for Mental Health (G3). The word ‘common’ is not defined, but is used to indicate moderate problems such as anxiety, depression and panic disorder, as opposed to major problems such as severe depression, manic depression, schizophrenia, personality disorder and dual diagnosis.

mental health continuum

Terms to describe the continuum of experience, in rising severity of need, from mental health to mental illness:

mental health - an individual’s ability to manage and cope with the stresses and challenges of life.

mental health problem – a broad range of emotional and behavioural difficulties, which vary in how much distress they cause and the extent to which they interfere with everyday living.

mental health disorder – problems are more severe and complex, to the extent that they cause serious interference with a person’s everyday life, and persist over weeks and months.

mental illness – mental disturbance is so severe as to cause even greater distress and confusion for the person and those caring for them, with the person having a precarious hold on reality and the disturbance interfering substantially with their daily life and relationships.

neurosis and psychosis

Neurosis is a normal feeling, such as anxiety and depression, that has become seriously out of proportion. Neurotic illnesses include generalised anxiety disorder, phobias, obsessive-compulsive disorder, and neurotic depression.

Psychosis is not a normal experience. It involves distortion of a person’s view of reality, often accompanied by abnormal beliefs (delusions) and abnormal perceptions (hallucinations). Psychotic illnesses include schizophrenia, bipolar disorder (manic depression), psychotic depression, and puerperal psychosis.

co-morbidity, dual diagnosis, complex needs

The simultaneous presence of two or more disorders, such as combinations of severe mental illness, substance misuse, learning difficulties and personality disorder.

psychopathology

The scientific study of mental disorders.

specific conditions

affective or mood disorders (depression and manic depression)

A disturbance of mood, resulting generally in either depression or elation, which is often chronic or recurrent in nature. There are usually associated alterations in activity, sleep and appetite, plus symptoms of anxiety. Affective disorders vary greatly in severity and include unipolar affective disorder (depression) and bipolar mood disorder (manic depression).

anxiety

A mood state in which feelings of fear predominate and where the fear is out of proportion to any threat. Frequently associated with physical symptoms that include fast pulse rate, palpitations, sweating, shaking, 'pins and needles'. Anxiety disorders can include simple phobias, fear of a specific object or situation, generalised anxiety disorder, panic disorder, agoraphobia, obsessive-compulsive disorder, or post-traumatic stress disorder.

depression

A negative mood state that involves a feeling of sadness. A severe depression can reach the criteria for an affective disorder and require treatment. Depression frequently coexists with, and complicates, physical illness.

personality disorder

A term sometimes used to describe someone who does not fit into any other mental health diagnosis but does have difficulty coping with life and displays persistent behaviour that causes distress to themselves or others. The behaviour tends to arise in childhood and adolescence and persists during adult life but can be helped by long-term support and changes to the person's social environment. The disorder generally involves difficulty in personal and interpersonal functioning and in interpreting social cues.

phobias

These are a specific type of anxiety, defined as out-of-proportion fears. The person tries to avoid the feared situation, eg open spaces (agoraphobia), meeting people (social phobia), fear of particular animals (animal phobia).

post-natal depression

One of the most common complications of childbirth, which can last for months or years but can be cured if treated soon enough. The common symptoms are depression, irritability, fatigue, sleeplessness, loss of appetite and enjoyment, anxiety and not coping.

puerperal psychosis

A mental illness that usually starts within days of giving birth. The mother may feel suicidal or be deluded that her baby is evil. The illness is serious, but rare, arising after only one birth in 500.

schizophrenia

A severe psychosis during which the person's experience and interpretation of the outside world is disrupted. They may lose touch with reality, see or hear things that are not there, and act in unusual ways in response to these distorted perceptions and hallucinations. People may hold beliefs that seem impossible to others.

substance misuse

The continual use of a mind-altering drug, including alcohol, such that it interferes severely with a person's physical and mental health, social situation, functioning and responsibilities.

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