Improving opportunities and outcomes for parents with mental health needs and their children

A review of the implementation of Action 16 of the Mental Health and Social Exclusion Action Plan 2005-2008

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Preface

We know that parental mental illness can have serious impacts on the wellbeing of families. Parents with mental health problems can feel isolated and worried about the effect their illness may have on their children, while children can feel guilty, anxious and over-burdened. Services intended to provide safety and support can fail to promote recovery if the effects on the whole family are not taken into account. Equally, meeting the needs of affected families is not something that lies within the gift of any one organisation, which is why agencies have been working together to over-turn barriers and improve the responses they make to parents and their children.

For these reasons, Barnardo's seized the chance to work with the National Social Inclusion Programme/Care Services Improvement Partnership and other key partners to implement Action 16 of the government's Mental Health and Social Exclusion Action Plan (2004). The main other organisations involved were:

- Social Care Institute for Excellence
- Liverpool Barnardo's Action with Young Carers/Keeping the Family in Mind
- Department of Health/National Children and Adolescent Mental Health Services Support Service
- Family Action (Formerly Family Welfare Association)
- Mental Health Act Commission

The key message of the Action 16 programme was 'think family'. Through awareness-raising, sharing and disseminating knowledge and developing resources for positive practice, it has successfully influenced emerging policies and work-streams across children's and adult services to focus more clearly on improving outcomes for families.

The Action 16 partnership demonstrates how agencies from health, social care and the voluntary sector working closely together can achieve positive change for vulnerable families. Resources such as the 'Keeping the Family in Mind' pack, which was developed in partnership with Action 16 and is discussed in detail in this report, provide excellent examples of what can be achieved when practitioners and policy-makers put the needs of children and families centre stage. Through its collaborative approach to influencing change, Action 16 provides a model for addressing how services are delivered to families from which future initiatives can learn.
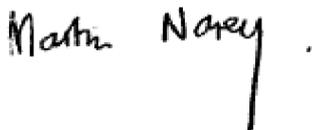
Martin Narey

Martin Narey

Chief Executive, Barnardo's

Introduction

Between 30% and 50% of users of mental health services are parents with dependent children. These families include some of the most disadvantaged and socially excluded adults and children in our society. There is currently no routine identification or assessment of mental health service users as parents. Where service users are not visible as parents it means a core aspect of their lives and identities is ignored; it also means that the needs of their children can be entirely overlooked. This can expose children to additional hardship, and in a few cases, serious risk of harm. Even when mental health service users are identified as parents this all too rarely results in access to family support services.

It was therefore significant that the Social Exclusion Unit (SEU) in their 2004 Mental Health and Social Exclusion Action Plan identified parents with mental health problems and their children as one of the four groups most likely to face barriers to getting their health and social care needs addressed. The section in the plan which addressed the needs of this group was 'Action 16', and this quickly became shorthand for the work of the collaborative set up to oversee its implementation.

This report analyses the work of the Action 16 outcomes partnership 2005 – 2008, which aimed to find ways of improving opportunities and outcomes for parents with mental health needs and their children.

The review

Researchers from Barnardo's and DMSS Research & Consultancy were commissioned to undertake this review of the Action 16 programme in July 2008. We were concerned to review both progress and process: to address what had been effective in influencing change, in what contexts and by what means. The Action 16 partners were keen that the lessons of the partnership as a method of promoting service improvement be captured and communicated in ways that might be helpful to others. This report therefore provides an overview of the Action 16 programme of work, its objectives and activities, and a contextual analysis of the extent of its success in achieving them.

Information for the review was gathered from key documents, including policies and action plans, and through interviews with key stakeholders involved in Action 16. These informants were:

- Aileen Alexander (Barnardo's Action with Young Carers, Liverpool)
- Rose de Paeztron (Family Action)
- Marie Diggins (SCIE)
- Deborah Jamieson (Department of Health)
- Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts)
- Clare Mahoney (CSIP)
- David Morris & Christa Drennan (NSIP)
- Vicky Nicholls (Parental Mental Health and Child Welfare Network)
- Louise Wardale (Barnardo's Keeping the Family in Mind, Liverpool)

The authors would like to extend their thanks to these informants for their contributions.

Ⅰ Child and Adult Services: Partnership in Action

The Mental Health and Social Exclusion Report

In June 2004, the Social Exclusion Unit published the *Mental Health and Social Exclusion* report, which addressed the social and economic costs of mental health problems and the impact of mental illness on family well-being and child development. Included within the report was a 27-point Action Plan that described working across service areas and government departments, to improve access to social participation, employment and services for those affected by mental illness (SEU, 2004).

Action 16 of the Plan identified parents with mental health difficulties and their children as one of the four groups at most risk of facing barriers to health and social care services.

> *It was a first: that report was a catalyst for real change.*
> Marie Diggins (SCIE).

While improving the lives of excluded groups by reducing barriers to social participation was one of the key aims of the Plan overall, Action 16 focused on enhancing opportunities and outcomes for parents with mental health needs and their children.

A partnership approach to effect change

The initial strategy for implementing Action 16 was to establish a partnership that would achieve change by working across adult and children's systems to promote policies and practice that considered the needs of whole families rather than regarding their service users solely as people with individual difficulties and needs. This more family focussed approach was named 'think family'. The name 'Action 16' was adopted by the stakeholder group set up to manage the strategy's implementation, through a three year programme of activities from 2005-2008. The steering group was led by NIHME/CSIP's National Social Inclusion Programme and the Social Care Institute for Excellence (SCIE), and involved key partners from across the health, social care and voluntary sectors, to provide the overview and skills needed to bridge the gap between child and adult policy and services (Keeping the Family in Mind: Summary Paper, June 2008)[1]. Strategic links were also established with sections of the Department for Health and the Department for Children, Families and Schools, professional networks and NIMHE/CSIP programmes.

Membership of the Action 16 group was largely self selecting because many of the partners were already working towards improving outcomes for affected parents and children.

Family Action was involved with Action 16 because we were already working across adult mental health services and CAMHS. We were one of the few organisations that were already working in a family context and overcoming the tensions and barriers that this creates.
Rose de Paeztron (Family Action).

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[1] Partners involved in the Action 16 programme included the Mental Health Act Commission, Barnardo's, Family Action, the National CAMHS Support Service, the Parental Mental Health and Child Welfare Network, Young Carers Associations including the Princess Royal Trust for Carers and the Mental Health Foundation, the network for Safeguarding Leads in Mental Health Trusts

The partnership approach was important for a number of reasons. It enabled members to draw upon the power of an active and expert group rather than working in isolation. It also provided opportunities to share knowledge, make links with influential stakeholders and identify and exploit opportunities to influence policy and practice.

> *It was partnership and collaboration. And to me that was the cornerstone, to springboard the work. What that meant was that no-one was in this at a competitive level, it was non-competitive. It was cornerstone that we were all there because we shared the same view that we want better outcomes for families who are affected by parental mental ill health. For me, it was my big opportunity to keep on talking about why these children are invisible, why are they still slipping through the net, why are we getting it right in some bits of the system but not in others.*
> Louise Wardale (Barnardo's Keeping the Family in Mind).

> *I thought the idea of a ... non competitive process at the centre of the ethos was very good, excellent really.*
> Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts).

The programme sought to listen to families and understand their attitudes and experiences through consultations with family members and practitioners. This led to the development of resources such as the *Keeping the Family in Mind* pack and *Ten Key Messages*, which have raised awareness and highlighted examples of good practice as well as difficulties within the system (Keeping the Family in Mind – Summary Paper, June 2008).

> *At the project the staff were continuously listening to what Young Carers and their families were saying. We wanted to ensure that their voices and messages were fed into the relevant systems so that they could be heard at different strategic levels.*
> Aileen Alexander (Barnardo's Action with Young Carers, Liverpool).

The relationship with SCIE was particularly significant, because they were leading the development of national practice guidance on parental mental health and child welfare. This relationship was underlined by a specific Action 16 objective, which described supporting and promoting the work of the SCIE review and in turn ensuring that Action 16's work was informed by the evidence base (Objective 2, Action 16 Implementation Plan 2005). Through the membership, connections were made to the whole system.

> *The whole is more than the sum of its parts: Working in partnership to a common aim with such a diverse and dedicated group, including Family Action, SCIE, Barnardos was key to achieving so much.*
> Christa Drennan (NSIP)

Action 16's objectives

Action 16 worked to implement three overall policy objectives, as follows:

● To improve understanding and capacity within adult mental health services to support parents and children, manage risk and reduce negative impact.
● To improve understanding within early years sectors of the needs of parents with mental health problems.
● To secure a higher profile for parental mental health and children's needs at appropriate levels within regional and government organisations.

These objectives were, to varying degrees, successfully pursued over the lifetime of the Action 16 group, through the development of resources and networks, awareness raising and influencing key systems and emerging policies to 'think family'.

> *It [Action 16] was very positive. [It] raised the profile of parental mental health and whole family approaches.*
> Deborah Jamieson (Department of Health).

Action 16's objectives are reflected in its implementation plan, developed in November 2005, which set out the activities of the group for the duration of the three-year programme. Embedded within the plan were the values and principles of the Action 16 group, which was committed to ensuring service user and carer involvement, partnership working and tackling discrimination and prejudice (Action 16 Implementation Plan, 2005).

Summary

This chapter has described the development of the Action 16 group, its objectives and implementation plan. The following chapters will explore the processes it used to improve outcomes for families through influencing emerging policies and practice, as follows:

● Using evidence to effect change

● Resource development

● Using networks to effect change

● Influencing specific policies

2 Using evidence to effect change

The potential adverse effects for families where a parent suffers from a mental illness have been widely discussed. Research has described the impact on child development, well-being and safety, and there have been numerous calls for adult mental health and children services to work collaboratively to meet the needs of families. However, it has also been recognised that actual service improvement had been patchy and slow.

Action 16 provided an opportunity to try and increase the pace of change, providing a base from which new and existing evidence could be disseminated and tangible change in both policy and practice could be monitored.

This section demonstrates how Action 16 used both new and existing evidence to attempt to increase the pace of change. By collecting evidence from service users and carers, evidence from current practice provision and evidence from experts within the field, Action 16 was able to advocate for the importance of 'thinking family' if services are to meet the needs of families experiencing parental mental health.

Influencing Policy

Sure Start Children's Centres Practice Guidance
One of Action 16's objectives was "to seek partners in influencing the development and implementation of policy and practice in the early years." Links were made with Sure Start leads at the Department of Health. A 'writing workshop' was set up, involving experts from a range of sectors and disciplines to produce a draft of the guidance on mental health. Evidence from existing practice and policies, such as the Mental Health Foundation's *Brighter Futures* report (1999) and the National Service Framework for Children, Young People and Maternity Services was drawn upon.

The guidance produced embeds the messages advocated by Action 16. Section 13 entitled "Mental Health", and makes it clear that parental mental health should not only be the concern of adult mental health services, but also children's services.

> *A parent's mental ill-health can have an effect on the mental health and development of their child.*
> (Sure Start Children's Centres Practice Guidance, 2006: 76)

The document also states that 'thinking family' is the best way to protect the mental health and wellbeing of children.

> *In order to promote good mental health in parents and children, children's centres should be aware of what it is that families need to ensure good mental health.*
> (Sure Start Children's Centres Practice Guidance, 2006: 76)[2].

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[2] The Sure Start Children's Centres Practice Guidance can be found at http://www.surestart.gov.uk/publications/?Document=1854

The National Carers Strategy

The core task of Action 16 was to make children and families visible in the context of parental mental health. Addressing the needs of young carers was considered especially important, given issues such as the fact that they are the least likely group of carers to be offered a carers assessment. Exploring the implications of the government health and social care white paper, 'Our Health, Our Care, Our Say' (OHOCOS, 2006) was therefore an obvious priority. At the outset there were some concerns that particular features of OHOCOS, including its person-centred focus, might 'miss the mark' with families because of the invisibility of both young carers and patients as parents.

In order to address these concerns, a Health Impact Assessment (HIA) was commissioned by CSIP to identify the potential health effects of the implementation of OHOCOS on young carers in England, including the differential distribution of these effects at a regional level.

The HIA of the OHOCOS white paper took place between May and October 2007[3] and was informed by data from:

- Focus groups with young carers' workers and young carers;
- An analysis of national policy;
- A review of the evidence from literature; and
- Interviews with other interested stakeholders.

Data from the focus groups was uploaded onto a national consultation website, to contribute to the evidence base that was submitted to the Review of the National Carers Strategy and help ensure that the need to "think family" was reflected in the 2008 National Carers Strategy.

> *They asked for more support for parents to be parents, for the family to be a family, and for support to give them the time and space they needed*
> National Carers Strategy, 2008:133.

Influencing Practice

Parents in Hospital

One of Action 16s objectives, set out in its Implementation Plan, was as follows:

> *To co-ordinate a review of family visiting facilities within hospitals, including quality of provision, access to it and attitudes towards family visiting and young cares when a parent is in hospital.*
> Social Networks/Action 16 Implementation Plan, (2005)

The review was undertaken in 2006, by staff in Barnardo's Policy and Research Unit in partnership with the Mental Health Act Commission (MHAC) and CSIP [4].

[3] Abrahams, D and Pennington A (October 2008) *A Rapid Health Impact Assessment of 'Our Health, Our Care, Our Say'* on Young Carers IMPACT/University of Liverpool
[4] The full report and executive summary can be found at:
http://www.barnardos.org.uk/search.htm?Go=Search&qt=parents+in+hospital&ql=&charset=iso-8859-1&col=mainsite

The Parents in Hospital review drew on the views and experiences of a range of informants, including staff working in in-patient adult mental health services and both current and previous patients who were parents. Children of parents who had been hospitalised with mental health problems also contributed. This ensured that service user and carers voices were heard.

As part of the review Mental Health Act Commissioners inspected 60 hospital visiting facilities using agreed criteria and obtained copies of the hospital or Trusts Family Visiting Policy. This allowed current policy, facilities and practices to be considered alongside the views and experience of staff, patients and children.

The review found a lack of correspondence between good policies and good practice. While many Trusts had good policies on family visiting, only five out of 39 services had facilities and arrangements for family visiting which were identified as 'good'. A total of 21 services were deemed 'adequate', and 13 were judged as 'poor'. In 17 units, there were no toys or activities available for children, and amenities for older children were found to be extremely limited across the sample of services.

The consultations with staff, parents and children highlighted a considerable gap between the perspectives of staff and those of patients and young people. Often, parents and children were considerably less positive about visiting conditions than were staff. Parents and young people highlighted how the stigma often attached to parental mental illness impacts on the difficulty of maintaining positive family contact when a parent is in hospital.

The report of this review, published by Barnardo's, made the following recommendations:

- Many Mental Health Trusts need to address a significant gap between what they say in their policies on family visiting and what is done in practice in in-patient services.
- Contact between parents and children when a parent is in hospital needs to be actively encouraged by staff.
- Staff need information and training to increase their:
- Knowledge of the benefits to parents children of contact
- Confidence in addressing family issues with patients
- Skills in communicating helpfully with children and young people
- Ability to challenge the stigma of mental illness and the barriers that it creates between parents, carers and children
- Family visiting rooms which are accessible, warm, clean and well-equipped should be available in all in-patient units/hospitals.
- Patients, carers and their children should be actively involved in the development of family visiting rooms
- All new-build facilities should incorporate family visiting rooms in their design
- Finally, services should act on the 10 messages to mental health professionals written by a group of young carers in Liverpool (Barnardo's, 2005).

The report was widely disseminated electronically and in hard copies and presentations of the findings were made to interested parties including mental health trusts and at events such as Community Care Live. There is some evidence that the recommendations have been useful in influencing improvements to hospital family visiting facilities. Family Action, one of the Action 16 partners, has facilitated the development of a family room in Tower Hamlets St Clements hospital, which has been in place for two years. Geoff Allcock, the safeguarding lead for one of England's biggest Mental Health Trusts stated:

> *Here in Birmingham and Solihull we've recently opened several new facilities and each individual in-patient clinical area (I think 9 or 10 in total) has a family visiting room included in the design from the start.*

Safeguarding Children within Mental Health Trusts

As a result of the networking within Action 16, and between Action 16 and safeguarding leads, it emerged that many safeguarding leads in mental health trusts were carrying the children's agenda within adult focussed organisations from positions of some isolation.

The purpose of setting up a national network for safeguarding leads in mental health trusts was two-fold: to strengthen the role of safeguarding children leads as champions of parents and children within mental health systems; and to provide opportunities for them to network and explore issues specific to their role and experience.

Of the 74 mental health trusts within England, 60 are members of the Safeguarding Children's Network. Between 2007 and 2008, in partnership with Action 16 organisations, they helped contribute to a number of initiatives in particular a design workshop on positive practice across the whole system; an indicative scoping of investment *in safeguarding children in mental health trusts.*

The scoping exercise found that Investment in safeguarding children in mental health trusts varies greatly across organisations and recommended that local health economies review whether their existing investment in mental health trusts was sufficient..

Overall, the exercise has produced evidence on which future strategic discussions can be based:

> *It was helpful to see and to know where you are in the grand scheme of things.*
> Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts)

This work will continue through the 'National Network for Named Professionals for Safeguarding Children in Mental Health Trusts' who state in their 2008 business plan that they will disseminate the findings from the scoping exercise nationally and plan to contribute to the development of a national standard of good practice.

Summary

This section has shown how Action 16 used new and existing evidence to effect change. Action 16 successfully:

- Helped influence the Sure Start Children's Centres Practice Guidance and the National Carers Strategy, ensuring that the policies recognise families and make visible the hidden needs of parents and children.

- Influenced improvements in hospital family visiting facilities, ensuring that service users' experiences are paramount and that children are thought about in the provision of adults' mental health services.

- Influenced the strategic discussions that are taking place to think about the nature of Safeguarding Leads in Mental Health Trusts.

However, the real impact of these policy and practice developments will become clearer over time.

The proof...will be in the quality of the implementation and there I think there are service complexities and service configuration issues... that's what needs to be seriously tackled now.
David Morris (NSIP)

③ Resource Development

Action 16 was involved in the development of a number of practice guides, motivational tools and resources, some of which grew out of direct work listening to children and parents. Action 16 supported the development of resources by contributing funding to their publication and promoting their dissemination through adult mental health networks. This included the 'Keeping the Family in Mind' resource pack, the For Children's Sake anti-stigma postcards and posters.

Members of the collaborative have also promoted the development of SCIE/NICE guidelines on parental mental health and child welfare.

This section describes these resources, including their development, dissemination and impact, and shows how they were both supported by, and supported the aims of, Action 16.

Keeping the Family in Mind pack
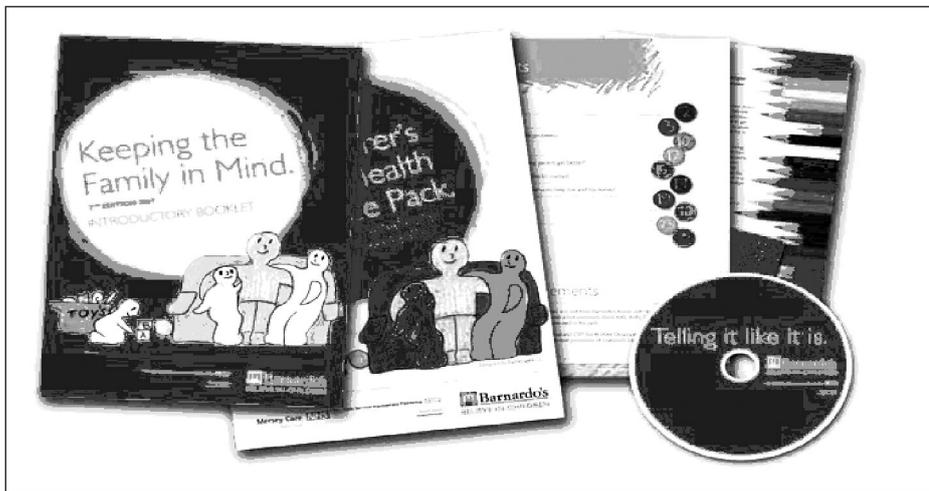
The *Keeping the Family in Mind* (KFIM) pack was originally developed by Barnardo's 'Action with Young Carers' service in Liverpool. In 1999, the service undertook some qualitative research exploring people's experiences of mental health systems and services, which informed the development of a new project called KFIM in Liverpool.

Young carers involved in the research and its dissemination developed ten key messages that would help to improve young people's experience of having a parent who suffers from mental health.

The ten messages read:

1.   Introduce yourself. Tell us who you are and what your job is.

2.   Give us as much information as you can.

3.   Tell us what is wrong with our parents.

4. Tell us what is going to happen next.

5. Talk to us and listen to us. Remember it is not hard to speak to us; we are not aliens.

6. Ask us what we know and what we think. We live with our parents; we know how they have been behaving.

7. Tell us it is not our fault. We can feel really guilty if our mum or dad is ill. We need to know we are not to blame.

8. Please don't ignore us. Remember we are of the family and we live there too.

9. Keep on talking to us and keeping us informed. We need to know what is happening.

10. Tell us if there is anyone we can talk to. **MAYBE IT COULD BE YOU.**

The KFIM pack was produced with the full participation of service users and young carers. It provides practitioners and commissioners with simple messages about how service provision can be improved and it raises awareness of issues regarding parental mental health. A DVD entitled 'Telling it like it is' was also produced to convey the ten messages and promote understanding of young people's experiences and perspectives. In 2007, a second edition of the KFIM pack was published, which Action 16 funded and enabled the Barnardo's project to disseminate nationally.

> *What Action 16 allowed us to say was 'let's go for a second edition. Let's make more of a national feel to it. Let's take the learning from it.*
> Louise Wardale, (Liverpool KFIM and Young Carers project)

The KFIM pack has been very positively received.

> *The ten key messages have been fantastic. So down to earth, so simple and they provide a check list that professionals can use.*
> Vicky Nicholls (PMHCWN)

> *The ten key messages that had been established were messages that we as leads had all been thinking about...That piece of work was what we needed.*
> Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts)

Anti-stigma postcards and pictures

My mum worries her children will be taken off her

For children's sake, please change your attitude towards people with mental illness

my dad has depression, sometimes i get upset

For children's sake, please change your attitude towards people with mental illness

It doesnt help when people call my dad a nutter

For children's sake, please change your attitude towards people with mental illness

As part of the raising awareness agenda, CSIP and Barnardo's KFIM project also developed ten postcards and three A2 size posters. The resources were intended to challenge the stigma associated with parental mental illness by raising awareness of the distress caused to children and formed part of the 'For Children's Sake' anti-stigma campaign on World Mental Health Day, October 10th 2007.

Development of SCIE/NICE practice guidelines

The SCIE/NICE guidelines arose from a recommendation set out in the SEU'S Social Exclusion and Mental Health report (2004):

> *DH will commission the Social Care Institute for Excellence (SCIE) to conduct a systematic review of evidence and existing practice by health and social care services in parenting needs, including meeting the needs of minority ethnic patients; and to publish new guidelines. In developing these guidelines, SCIE will, if appropriate, collaborate with the National Institute for Clinical Excellence. (p105).*

The project had two main aims[5] :

● To undertake a systematic review of existing practice by health and social care services with parents with mental health problems and their children.

● To use the findings from the review to:

· Publish guidelines for health and social care staff in mental health and children and family services.
· Produce a national strategic plan for guideline implementation and review
· Identify service areas that would benefit from national performance indicators and be a focus for health and social care inspections.

[5] This information is taken directly from SCIE/NICE systematic review and guidance brief, 2005.

·   Identify further areas for research and development if application.

There were three planned phases to the project: a scoping review, a systematic review, followed by the development of guidelines and a cross government implementation plan. As part of the systematic review, a practice survey was conducted in five practice sites across England in order to provide real-world intelligence on the way services work together.

Through its links with SCIE and the Parental Mental Health and Child Welfare Network, Action 16 was closely involved in the development of the review and the practice guidelines. This fulfilled Objective 2 of Action 16s implementation plan, which described supporting and promoting the work of the SCIE review and ensuring that Action 16's work was informed by the evidence provided by the review.

The development of the review and the practice guidelines is vital, because there is currently no national evidence-based resource for improving outcomes for the whole family and raising standards among professionals. The practice guidance will be an online resource, consisting of concise and user-friendly information with recommendations for professionals. The guidance is due to be published in late 2008 and will include a performance assessment and inspection framework.

Summary

Through partnership work, Action 16 has informed and supported the development of a number of diverse and user-friendly 'think family' resources for professionals. Key among the resources for practice developed were:

- The *Keeping the Family in Mind* multi-media resource pack
- The *For Children's Sake Anti-Stigma* postcards/posters.
- The national practice guidelines on parental mental health and child welfare.

These resources are important, because they have the potential to affect the practice of individuals, teams of professionals, and the wider organisations within which they work:

> *It's very much about changing the culture of service provision... 'keeping the family in mind' is something that needs to made real in the everyday work of people in social work departments; in Trusts and so on.*
> David Morris (NSIP)

4 Developing networks and collaboratives to effect change

Action 16 attached a great deal of importance to developing and liaising with practice networks. These were recognised as key agents for change through influencing professionals working with parents and children to 'think family' (Objective 7, Action 16 Implementation Plan 2005). During the course of its programme of work, Action 16 liaised closely with two practice networks of this nature:

- Parental Mental Health and Child Welfare Network (PMHCWN); and
- National Network for Named Professionals for Safeguarding Children Leads in Mental Health Trusts.

Both networks were significant for Action 16, in terms of representing opportunities to engage practitioners whose work has a direct impact on vulnerable families. Through bringing key professionals together, the networks provided Action 16 with a link to 'real world informants' and:

- Acted as a framework for sharing and disseminating good practice, research and resources;
- Provided leadership and confidence for professionals; and
- Addressed important issues in a collaborative manner.

The following sections describe Action 16's relationship with these practice networks and how they contributed to developing and disseminating 'think family' practice and policies.

Supporting practice networks

The Parental Mental Health and Child Welfare Network was set up following the publication of the *Mental Health and Social Exclusion* report in 2004, and has had close ties with the Action 16 group since its inception. It was established by SCIE as a vehicle to promote joint working between children and adult's services and share information and practice examples, such as its forthcoming practice guidance[6]. The PMHCWN sets priorities via its steering group of representatives from mental health and children's organisations and service users, which ensures a focus on improving outcomes for families.

> *There has been a lot of cross-fertilisation because of our shared foundations.*
> Vicky Nicholls (PMHCWN).

By contrast, the National Network for Named Professionals for Safeguarding Children in Mental Health Trusts developed out of the need, identified by Action 16 and practitioners, for a national network that could build capacity within safeguarding systems and provide much-needed leadership and authority for safeguarding leads (Business Plan, July 2008). Action 16 recognised the importance of the role of named safeguarding professionals as a means of shifting organisational cultures focussing on individual patients to more family-centred outlooks.

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[6] The PMHCWN is now co-ordinated by the Social Perspectives Network, which aims to raise awareness and understanding of mental distress in terms of people's life experiences and promote social models of distress.

Partnership work with Action 16 brought many advantages to both networks. The Action 16 group offered support and guidance from a coalition determined to improve outcomes for children and families affected by mental illness.

> *There were really dedicated people involved, pulling together.*
> Vicky Nicholls (Parental Mental Health and Child Welfare Network).

In terms of financial support, Action 16 provided gap funding for the PMHCWN in 2007, while the network was in transition from SCIE to the SPN. The funding was also intended to give contingency and security to the PMHCWN, to allow it to explore other potential funding opportunities (CSIP/PMHCWN note, 2007). Through CSIP, Action 16 also provided start-up funding for the Safeguarding Network.

> *She* [Clare Mahoney] *got a little chunk of money and then she said this needs to be a national thing. We need a national lead, we need to pull this together, people need to be aware of the difficult agenda that being carried in specialist mental health services around safeguarding children. And we need a forum of our own.*
> Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts).

Action 16 also contributed to the Safeguarding Children Network through commissioning a scoping exercise across England of investment in safeguarding in mental health trusts (discussed in more detail in section 2).

Practice Networks as Agents for Change

Both the PMHCWN and the Safeguarding Children Network use their mandates to secure better outcomes for families affected by mental illness. The PMHCWN maintains a focus on raising practice standards to improve outcomes, while the Safeguarding Children Network's Business Plan (2008) emphasises the role of safeguarding leads as 'change agents' within local children's services and Mental Health Trusts.

The networks were identified by Action 16 as key levers for change because of their links to a wide body of practice and access to literally hundreds of professionals. The PMHCWN has a diverse steering group, which includes key Action 16 actors such as CSIP/NSIP and Barnardo's, and its 850-strong membership is open to all disciplines from adult mental health and children's services, service users and carers. It will also play a key role in the dissemination of the SCIE/NICE practice guidelines for parental mental health.

> *...the PMHCWN, [had] a membership of 800-900 practitioners from across the country. I think that's a tremendous bedrock of activity to do development work with.*
> Clare Mahoney (CSIP)

> *Our work was as much informed by them as their work was by ours.*
> Vicky Nicholls (PMHCWN).

Both networks have been instrumental in disseminating resources and good practice influenced by Action 16, through newsletters, study days, workshops, developing web-based sites and sharing and disseminating research and good practice. The practice networks also provide a potential source of trainers to disseminate resources such as *Crossing Bridges* and the *Keeping the Family in Mind* pack through training programmes.

> *...a lot of our work has been showcased on the study days that [the networks have had].*
> *Whenever I had done presentations it was about saying to people this is about different*
> *products, different strengths and different ways, but they're all connected because they're*
> *about experiences from families.*
> Louise Wardale (Barnardo's Keeping the Family in Mind).

The networks have also directly influenced 'think family' policies and practice. They act as a key resource to build confidence among professionals to 'think family'. The Parents in Hospital review highlighted that many adult health professionals were reluctant to deal with patients' children, because they felt they lacked the knowledge and skills to do so. Through sharing good practice, knowledge, resources and research, the practice networks provide a link to the workforce that will be vital in affecting meaningful change in policy and practice.

A Whole Systems collaborative

The FAMILY Collaborative in Liverpool is an outcomes collaborative launched in September 2007. It aims to 'ensure the continuing development of family-focused policies, services and systems for children and families affected by mental ill health in Liverpool' (Liverpool FAMILY Collaborative: Update on activity). The collaborative follows a quality improvement methodology that uses Plan-Do-Study-Act (PDSA) cycles in order to test ideas in small increments before change is rolled out to the whole system.

Since the first 'Learning Event' took place in 2007 over 200 staff have been involved in a over 30 PDSA cycles , covering a range of services and issues across the city including Children's Services, Education, Specialist Mental Health Services, Voluntary Sector Providers and Commissioning bodies

A wide range of improvements to practice and policy have been reported (see ref) and importantly the collaborative is seen as having increases in ownership at senior levels across child and adult care sectors alike. There has been a recognition of the impact of sharing learning across adults and children's' systems and that this had resulted in many *'successes in the "too hard to do" category'* (Liverpool FAMILY Collaborative: Update on activity).

> *It's about motivating parts of the system, because these children and families don't live in one*
> *part of the system.*
> Louise Wardale (Barnardo's Keeping the Family in Mind).

Summary and next steps

The practice networks have provided leadership, raised the profile of family focussed approaches, through influencing, sharing and promoting family-focussed approaches and policies. The PMHCWN will continue to share good practice and contribute to research and development initiatives, as it will have a key role in disseminating the forthcoming SCIE/NICE practice guidelines. In its Business Plan, the Safeguarding Children Network sets out its future priorities to include advocating for the needs of affected children and families in mental health trusts and continuing the promotion and dissemination of tools to support safeguarding practice. The FAMILY collaborative in Liverpool also looks set to have a long and useful life in promoting whole systems change at the local level.

5 Action 16: Influencing specific policies

Objective 3 of Action 16's Implementation Plan set out to identify and influence emerging policy drivers, liaising directly with the Department of Health, the Department for Children, Schools and Families (DCSF, formerly DFES) and regional structures. Action 16 placed an emphasis on influencing policy for a number of reasons:

Policy and operational frameworks can be barriers to 'think family': There is currently no national approach for improving outcomes for the whole family – and the growing number of national frameworks and strategies linked to specialist areas would appear to propagate existing barriers (SCIE/NICE brief, 2005).

The cross-cutting nature of the issues: Action 16 recognised that control of adult mental health, children and family policies is spread across a number of different government departments, including the Department of Health, the DWP and the DCSF. Action 16 advocated that some issues need to be jointly and visibly owned by departments.

> *It falls between policy areas and doesn't have a government department that provides clear leadership. In policy terms, it a bit of an orphan.*
> Clare Mahoney (CSIP).

The need to put family thinking into adult mental health policy: One of Action 16 programme's key objectives was to secure a higher profile for parental mental health and children's needs, as measured by influencing emerging policy and work streams.

> *Action 16 has put the family at the centre of thinking and policy development so that there is a recognition that mental health services users are also often parents whose illness will have an impact on the whole family, including the children.*
> Aileen Alexander (Barnardo's Action with Young Carers, Liverpool).

Over its lifetime, Action 16 directly influenced a number of key policy developments that have the potential to significantly impact on the quality of services received by parents with mental health problems and their children. Two examples of effective policy influencing are described in more detail below.

Influencing the review of the Care Programme Approach (CPA)

The CPA was established in 1991 to improve care services for people with severe mental illness. It is significant in that it provides an assessment, planning and review system, co-ordinating activities across a variety of services, for anyone accessing specialist mental health services[7].

In 2007, a review of CPA policy and implementation guidance was undertaken, in order to examine new ways of improving delivery of the CPA. A document titled Refocusing the Care Programme Approach was published in 2008, which drew upon examples of good practice across England.

[7] For more information see http://www.nimhe.csip.org.uk/our-work/reviewing-the-care-programme-approach-cpa-.html

Action 16 successfully influenced the Department of Health to prioritise parents with mental health problems under the reviewed CPA. In April 2008, SCIE, CSIP North West and the Department of Health produced a CPA briefing entitled *Parents with Mental Health Problems* and their Children, which describes the potential of the CPA to improve outcomes for affected families and the importance of dealing with the needs of parents with mental illness and their children[8]. The briefing sets out key issues to address, such as safeguarding, young carers, early years and the importance of supporting recovery and family life. It also describes how the CPA should be implemented for parents with mental health problems.

The CPA guidance underlines the importance of understanding the service user in the context of their family and environment rather than just as 'an individual with an illness':

> *There is enormous pressure on statutory services to deliver and, as in most jobs; you do what you have to do first. So, if there's nothing in the guidance that mentions parenting and children, it doesn't feature...That is why the new CPA guidance is a major step forward.*
> Marie Diggins (SCIE), quoted in *Mental Health Today*, May 2008.

> *They* [Action 16] *have got into every document that's around...for example, the CPA review, which was essentially repeating what Action 16 had said.*
> Vicky Nicholls (PMHCWN).

According to informants to this review, positive feedback on the CPA guidance has been received from professionals, including safeguarding leads, who work with children and families.

> *It's great to know that it's being used by practitioners.*
> Marie Diggins (SCIE).

Healthcare Commission: Influencing Acute Inpatient Care Standards

The Healthcare Commission's review of acute inpatient care standards grew out of a need to update existing national policy to ensure that it complemented changes in mental health care, such as treatment and care in the community. In 2006/07, it conducted an assessment which examined the quality of care provided by NHS acute inpatient mental health wards in England. Four key criteria were established, against which wards' performances were assessed, as follows: whole person care, service user and carer involvement, safety, and infrastructure to promote change.

The review of acute inpatient care standards represented an ideal opportunity for Action 16 to push the family thinking agenda in adult mental health policy. Action 16 had been involved in a number of initiatives relating to adult acute inpatient services such as the SCIE/NICE cross-cutting practice guidance and the Parents in Hospital review. It drew upon this evidence base to influence the development of the Healthcare Commission review criteria, upon which the assessment framework was based. Action 16's submission used the inpatient standards review to raise awareness of young carers, the importance of providing safeguarding training for staff and access to a named safeguarding lead.

[8] Diggins, M and C Mahoney (2008) Parents with mental health difficulties and their children (Satellite briefing to Refocusing of the Care Programme Approach). SCIE/CSIP. Briefing can be found at http://www.cpaa.co.uk.

Significantly, Action 16's input to the development of the assessment framework helped to ensure that the needs of parents as parents were acknowledged, for example, through the addition of an indicator in the final assessment framework relating to *'arrangements in place to support carers and families'* [9]. In July 2008, the results of the review were published. Among its main findings was that 40 per cent of the mental health trusts involved scored poorly in terms of involving service users and carers.

Summary

This section has described the importance of influencing policy to improve outcomes for families affected by parental mental illness, and two examples of key policy developments directly influenced by Action 16 that embedded family thinking in policy development – the CPA review and the Healthcare Commission Inpatient Standards Review.

Throughout its lifetime, Action 16 used its expertise and to raise awareness and understanding of family-focused thinking. Clearly the long term impacts of its work are likely to vary.

> *From my point of view the most influential changes with long term impact on adult services are going to be the changes in CPA that Action 16 contributed to.*
> Christa Drennan (NSIP)

However, some informants believed that the programme's lobbying work will continue to produce fruit in the future, as knowledge is disseminated and more policy makers and practitioners recognise the importance of 'thinking family'.

> *It's very hard to measure and I think that's the difficulty around strategic work sometimes – it's hard to see because it's not always a direct outcome. But finally people connect and penny drops and they say ah, they get that it's important for me and for children.*
> Louise Wardale (Barnardo's Keeping the Family in Mind).

[9] See Healthcare Commission document
http://www.healthcarecommission.org.uk/_db/_documents/AIPMH__summary_of_changes_to_assessment_framework_.pdf

Conclusion: an appraisal of the Action 16 programme

This report has described the original objectives of the Action 16 initiative and some of the activities used to achieve them. This section provides an overview of the future of 'thinking family' in policy and practice, and summarises the legacy of the Action 16 programme.

Next Steps

It is important that the values and practices promoted by Action 16 remain embedded within service provision and professional consciousness. Despite positive developments such as the publication of the 'think family' report by the SETF in 2008, evidence gathered from informants to this review suggests that there is still some distance to travel, with regard to overcoming structural barriers, changing attitudes and promoting understanding.

> *It's very much about changing the culture of service provision – keeping the family in mind is not a motto, it's something that we need to really have people achieve in the way they do their work and there is still a way to go.*
> David Morris (NSIP).

Stakeholders provided suggestions as to what needed to be in place to ensure this, including:

- Commitment and leadership from senior partners in social care and mental health trusts.
- Continue to raise awareness around persisting problems in the system, such as AMHS professionals ignoring patients' children because they assume that they are receiving support from elsewhere (e.g. social workers).
- Improve communication and working practices between children's and adults' services.
- More local work around the development of services across boundaries within local authorities.
- Continue to pursue a partnership approach to change –*'a federation of organisations needs to be working away on this.'* David Morris (NSIP).

Although the Action 16 programme of work has been completed, a number of the policies and resources that it has influenced are still to be finalised. These include:

The Draft National Clinical Practice Guideline on Borderline Personality Disorder (BPD): Recent NICE guidelines on Borderline Personality Disorder (BPD) failed to recognise the significance of people with a BPD diagnosis who are parents, and made only one direct mention of children. This is despite the fact that 75 per cent of diagnoses of BPD are made of women of child bearing age. Through its response to the guidelines, which drew upon evidence from service users and research evidence, Action 16 successfully lobbied NICE to ensure that the parental role is recognised in the guidance. It is due to be published in January 2009.

SCIE/NICE Practice Guidelines: The forthcoming SCIE/NICE practice guidelines will provide much-needed cross-cutting and user-friendly guidance for health and social care. The guidance will provide an online resource, concise information and recommendations that will be helpful for practitioners. Through

the publication and dissemination of the guidance, and in its role as a standard bearer for positive practice in social care, SCIE will continue to play a part in pushing the 'think family' message forward in the future.

Other key 'think family' developments

Many informants to this review commented that thinking family is now firmly embedded within the consciousness of policy makers and many practitioners. The following documents show how far the agenda has travelled since 2004, with a growing number of government initiatives stressing the importance of family-focussed approaches.

Families at risk review: From 2007 to early 2008, the Social Exclusion Taskforce carried out the Families at Risk review. This review aimed to explore ways 'to break through barriers in offering whole family support'[10], especially to those families at greatest risk of experiencing social exclusion.

> *The review will look at how to reach vulnerable families experiencing multiple problems, analysis of the types of issues they face, identifying the role of public services integrating adult and child services better and looking at the role of parents and parenting help.*
> Social Exclusion Task Force, 2007.

Family Pathfinder sites: The DCFS has taken on the management of the Family Pathfinder programme, which aims to develop evidence of what works and share best practice. The Pathfinder programme will inform the implementation of 'think family' approaches, and will continue the partnership working advocated by Action 16 through dialogue with central government, local partners and the third sector[11]. A number of Pathfinder sites are being set up, each supported by a national implementation team, which will produce learning on how local areas can improve outcomes through thinking family.

The Legacy of Action 16

The purpose of this report has been to document the legacy of Action 16, describing the achievements and impact that Action 16 had on the parental mental health and child welfare agenda. Action 16s legacy is varied and is evident in policy documents, professional practice and service provision. It also exists in the consciousness of those networks and individuals who continue to pursue the aims of Action 16.

> *The THINK FAMILY initiatives, particularly the training pack and resources and also the research into the use and availability of family rooms are practical things people in adult services can easily relate to and therefore have immediate impact. The phrase itself has caught on and is used regularly by DH – this is an important change.*
> Christa Drennan (NSIP)

While many stakeholders felt it is too soon to assess the full contribution that Action 16 has made to progressing the 'think family' agenda, the programme has already left a trail of policy influence and resources that will continue to support the efforts of key players and networks contributing to the further development of the parental mental health and child welfare agenda.

[10]http://www.cabinetoffice.gov.uk/social_exclusion_task_force/publications/families_at_risk/
[11]http://www.cabinetoffice.gov.uk/social_exclusion_task_force/families_at_risk/pathfinders.aspx

Action 16 has helped to create momentum and articulate the importance of the parental mental health and child welfare agenda.

> *It [Action 16] was very positive. They raised the profile of parental mental health and whole family approaches.*
> Deborah Jamieson (DoH)

> *The legacy of the programme is that it has created a momentum for child and adult mental health in a way that had not been the case before. It sort of pinpointed the need and articulated well the importance of this agenda.*
> David Morris (NSIP)

Action 16 has supported and championed new policy directions such as 'think family'.

> *I believe Action 16 has helped mainstream the notion of "think family" in policy and some in roads have been made into mainstreaming it in practice. People will start to think it is the norm – they will be thinking family.*
> Marie Diggins (SCIE)

> *Action 16 has put the family at the centre of thinking and policy development so that there is a recognition that mental health services users are also often parents whose illness will have an impact on the whole family, including the children.*
> Aileen Alexander (Barnardo's Action with Young Carers, Liverpool)

Action 16 has listened to the voices of service users and carers to help shape the influencing agenda and motivate change at the service level.

> *I think that the children's voices have been heard. The voice of the child who has a parent with a mental illness. I don't think that anyone has crystallised those messages in the way they have been now.*
> Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts).

> *It was really about harnessing what children and family members were telling us and motivating, raising awareness and making other people think about these issues.*
> Louise Wardale (Barnardo's Keeping the Family in Mind).

> *They did a lot of excellent work with young carers.*
> Deborah Jamieson, (DoH).

Action 16 has supported the creation of networks that will continue to advocate the aims and objectives of Action 16. These networks will also impact positively on professional development and resource development.

Influential networks have been set up, which will continue to work behind the scenes to promote joined up working and family focused approaches.
Vicky Nicholls (PMHCWN).

Action 16 has helped to influence policy and practice in both adult and children's services, promote joined-up working and has raised important questions about the structure and systems in mental health services for safeguarding the needs of families.

They [Action 16] *pulled together something incredibly important because you have to remember how these systems are organised politically...it's not helpful to children of parents with mental illness because of the way that systems are organised and funded.*
Karen Johnson (National Network for Named Professionals for Safeguarding Children in Mental Health Trusts).

Action 16 provided a national platform for grassroots and local issues

What I'm chipping away at here in this locality in Liverpool, I'm able also to take it nationally. It's local stuff that's driving national work rather than the national agenda driving the local.
Louise Wardale (Barnardo's Keeping the Family in Mind).

There were developments happening both nationally and locally. Action 16 gave us that much needed formal link between the two.
Aileen Alexander (Barnardo's Action with Young Carers Liverpool).

Appendix 1: Mental Health and Social Exclusion Report 2004

1. **ACTION 16 – BETTER SUPPORT FOR PARENTS AND THEIR CHILDREN** (extract from the mental health and social exclusion report)

a. DH will commission the Social Care Institute for Excellence (SCIE) to conduct a systematic review of evidence and existing practice by health and social care services in supporting parents with mental health problems with their parenting needs, including meeting the needs of ethnic minority parents; and to publish new guidelines. In developing these guidelines, SCIE will, if appropriate, collaborate with the National Institute for Clinical Excellence. (SCIE from early 2005)

b. DfES will work with DH to ensure that the common core of training for professionals working with children and families addresses mental health issues. (DfES/DH from 2004)

c. DfES will encourage the emerging local structures for children and families' services to take explicit account of the needs of parents with mental health problems and their children, and collaborate locally with adult mental health services.

d. DfES will work with DH to help develop greater awareness in adult mental health services of the need to support parents with mental health problems in their role as parents. (DfES/DH from 2004)

e. DfES will help improve access to family and parenting support by:

2. highlighting the needs of parents with mental health problems and their children in the emerging family policy strategy;

3. Encouraging local Sure Start programmes, children's centres, other early years settings and other local statutory and voluntary services such as Home Start to be accessible and to reach out to and support parents with mental health problems and respond to their needs and those of their children. (from 2004)

   a. DH will give priority and seek appropriate funding for a review of the quality of and access to family visiting facilities within hospitals, and general attitudes towards family visiting and young carers when a parent is in hospital. (Review to be undertaken by 2006)

Other actions in the report fall into six main categories as follows:

- supporting families and community participation – enabling people to lead fulfilling lives the way they choose;
- stigma and discrimination – a sustained programme to challenge negative attitudes and promote awareness of people's rights;
- the role of health and social care in tackling social exclusion – implementing evidence-based practice in vocational services and enabling reintegration into the community;
- employment – giving people with mental health problems a real chance of sustained paid work based on their experience and skills;
- getting the basics right – access to decent homes, financial advice and transport;
- making it happen – clear arrangements for leading this programme and maintaining momentum

These actions contribute to a number of departmental Public Service Agreement targets, in particular:

- the Department for Work and Pensions' target to increase the employment rate of people with disabilities, taking account of the economic cycle, and significantly reduce the difference between their employment rate and the overall rate, and to work to improve the rights of disabled people and remove barriers to their participation in society;
- The Department of Health target to improve life outcomes of adults and children with mental health problems through year on year improvements in access to crisis and Child and Adult Mental Health services, and reduce the mortality rate from suicide and undetermined injury by at least 20 per cent by 2010.
- the Department of Health target to reduce inequalities in health outcomes by 10 per cent by 2010 as measured by infant mortality and life expectancy at birth; and
- the joint Department for Work and Pensions and HM Treasury target to reduce the number of children in low-income households by at least a quarter by 2004, as a contribution towards the broader target of halving child poverty by 2010 and eradicating it by 2020.

References

Barnardo's & CSIP, (2007) *Your second chance to Keep the Family in Mind*,
http://www.meridenfamilyprogramme.com/documents/currentissues/Barnardos_KFIM_advert.pdf

Barnardo's, CSIP and Mersey Care NHS Trust, (2007) *For Children's Sake: Anti-stigma postcards and posters,*
http://www.barnardos.org.uk/resources/research_and_publications/books_and_tools_health_and_disability.htm

Barnardo's, CSIP and Pearl Consultancy Services, (2008) *Liverpool FAMILY Collaborative: Update on Activity,*
http://www.northwest.csip.org.uk/silo/files/newsletter.pdf

Department of Health & Department for Education and Skills, (2006) *Sure Start Children's Centres Practice Guidance* http://www.surestart.gov.uk/publications/?Document=1854

Department of Health, (2008), *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own,*
http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345

Healthcare Commission (2006) Action 16s response to the Acute Inpatient Service Review

Jackson, C. (May 2008), *'Mental health services need to realise that patients may be parent too'*, Mental Health Today.

Knight, L., (2008) Safeguarding Resource for Children within Mental Health Trusts, Pearl Consultancy Services. Unpublished.

Mahoney, C. (2007), Action 16s submission to the Review of the National Carers Strategy New Deal for Carers.

Morris, J. (2007), *Building Bridges Evaluation*, London: Family Action
http://www.family-action.co.uk/uploads/documents/Building%20Bridges%20Evaluation.pdf

National Social Inclusion Programme, (2005), *Project Plan: Social Networks (Action 16)*, March 05-March 07,
http://213.121.207.229/upload/PlanOfActivity.pdf

Office of the Deputy Prime Minister, (2004) *Mental Health and Social Exclusion, Social Exclusion Unit Report*, London: ODPM

Parental Mental Health and Child Welfare Network, http://www.pmhcwn.org.uk/

Scott, S., B. Robinson and C. Day (2007), *Parents in Hospital: How mental health services can best promote family contact when a parent is in hospital*, Barnardo's/CSIP/MHAC/Family Action.

Royal College of Psychiatry, (2007), A presentation on the *Patients as Parents* online module

SCIE (2005), Project brief – systematic review of research about supporting parents with mental health problems and new practice guidance.

SCIE/NICE Parental Mental Health and Child Welfare Practice Guidance – (forthcoming).