

# 1 Project Brief

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The Mental Health and Special Programs Branch of the federal Department of Health and Aged Care commissioned AICAFMHA (see appendix 1 for more details) in August 1999 to carry out a scoping study regarding the provision of services to children with parents affected by mental illness. Investigating the availability of prevention and support programs for children of people with mental illnesses and developing recommendations for future action were national strategies identified in the Mental Health Promotion and Prevention National Action Plan (MHPP National Action Plan) (1999) (p. 33).

This plan was released in January 1999 under the Second National Mental Health Plan: 1998-2003 (1999), and it identified several other potentially important strategies in relation to these children:

- ❖ researching effective community-based interventions for children of parents affected by mental illness;
- ❖ evaluating the effectiveness and sustainability of prevention initiatives for consumers, carers and children with parents affected by mental illness; and
- ❖ developing positive outcomes for children with parents affected by mental illness, including improving support, mental health and parenting, reducing the occurrence of mental health problems or disorders, and promoting better knowledge and understanding of parental illness.

A range of national priority mental health targets are also relevant to families where one or both of the parents have a mental illness, including:

- ❖ promoting optimism, resilience, and social and emotional wellbeing for these children;
- ❖ engaging these families in mental health promotion and prevention programs;
- ❖ developing initiatives aimed at reducing the impact of risk factors on the mental health of all family members;
- ❖ enhancing parenting skills, child development and family functioning;
- ❖ promoting strong and positive attachments between parents and children; and
- ❖ promoting child and family participation in school and community activities.

It is in this context that the Commonwealth briefed AICAFMHA to carry out a scoping study regarding services for children with parents affected by mental illness. The project brief was as follows:

To undertake a project that will identify current major State and Territory evidence-based initiatives in relation to how each jurisdiction is addressing the needs of children of parents with a mental illness, and future plans for work in this area. It is expected that the project will result in a report that outlines major activities, identifies gaps and makes recommendations regarding future work and action in this area. Activities will include:

- ❖ gathering information from, and consulting with, State and Territory mental health branches on key projects and services for children of parents with a mental illness in their jurisdiction, and any future plans they have for work in this area; and
- ❖ analysis and reporting of project findings, including the evidence base of current activities, their availability and sustainability, and recommendations for future action.

For the purpose of this study, the term 'children' was defined as children and young people 18 years or younger. The project commenced in September 1999 and was completed by February 2000. Consultation with the National Mental Health Promotion and Prevention Working Party (PPWP) and the federal Department of Health and Aged Care regarding the recommendations was completed in July 2000.

## 2 Overview of Key Australian Reports

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When Mum got sick and we were alone with her, we didn't know where to get help. I was nine years old. We didn't understand what was happening, and did not know who to call, except dad, but we didn't know where he was or how to ring him. We were scared of mum and what she might do (Cowling 1999).

The commissioning of this report reflects an awareness by those who develop policy within our community that these children are experiencing unique challenges in their path to adulthood. It was not within the brief of this project to conduct a literature review of the relevant research regarding the experiences, outcomes and helpful interventions for these children and their families. However, a review of reports of recent Australian research, policy development, intervention and proposals or recommendations revealed a number of common themes and issues useful for consideration of the data received on current services.

Many of these reports were based on extensive reviews of the research literature dealing with these children and their families and they make practical recommendations regarding the translation of these findings into practice, as well as identifying available resources for children, their families and service providers (see chapter 8 and appendix 5). The following section of the report summarises these findings and provides an opportunity to review the problems the children, their parents and their extended families are facing.

As many of these reports were received opportunistically as the project officer developed contacts with practitioners in the field, rather than via an organised research strategy, it can be expected that other relevant reports do exist. However, consultation with the expert reference group has indicated that those reports identified comprise a good representation of what has been published in Australia about children in families affected by mental illness. The reports included:

- ❖ descriptions or evaluations of intervention programs (for example, Shipp 1996; Cuff & Pietsch 1997a and b; Cuff & Mildred 1998; Kraner 1998a and b; Pope 1998; and Cowling 1999);
- ❖ Australian research (for example, McGrath & Hearle 1998; Farrell et al. 1999; and Kalucy & Thomas 1999); and
- ❖ reviews of current policy and practice (for example, Burdekin, Guilfoyle & Hall 1993; O'Donovan 1994; Einfeld & McLaughlin 1998; McEnroe 1998; Cowling 1999; and Kowalenko et al. 1999).

As the original literature was not accessed for this report, comments cannot be made on the nature of the evidence base used in the literature to which these reports refer, and similarly no comment may be made on how rigorous was the scientific method used in each case. However, the research evidence quoted in all reports is very consistent.

A summary follows of the findings of the above reports on the number of adults with a mental illness who have dependent children and the prevalence of mental health problems experienced by their children. The impact of parental mental illness on the children is further described, as are the opportunities for mental health prevention and promotion and the issues and recommendations identified by previous reports.

### INCIDENCE

Recent Australian studies have begun to address the lack of data related to the number of children with parents affected by mental illness. However, statistical information is still sparse. Many adult mental health (AMH) services don't, or have only recently begun to, inquire and record whether their adult clients do have children. In addition, parents with a mental illness may not necessarily present to mental health services at all, or may not be willing to reveal the presence of children owing to fear of intervention or losing care of their children. However, Australian studies have found that, during the survey periods, anywhere between 29% and 35% of mental health service clients are female parents of dependent children under the age of 18 (Cowling 1999; Hearle et al. 1999; and Farrell et al. 1999). These mothers are likely to be in their mid-thirties and have very young children—that is, less than six years old—70% of whom are living with them (Farrell et al. 1999). In addition, around 30% of these clients also have a history of drug or alcohol abuse.

Farrell et al. (1999) also highlighted results from the West Australian Child Health Survey 2 (1993), which indicated that 13% of principal caregivers and 4% of secondary caregivers had been treated for a mental health problem, with

17% of all caregivers having been hospitalised for mental health reasons and 29% receiving some kind of mental health treatment in the last six months. Cowling (1999) also estimated, given current census data and accepted incidence rates of mental illness, that at least 27 000 Australian children are affected by maternal psychotic illness alone.

The reported prevalence of persistent emotional and behavioural difficulties among children who have a parent with a mental illness also varies greatly owing to differences in the way these difficulties are defined. However, the reported research consistently indicates much higher rates of emotional and behavioural problems, for example (Farrell et al. 1999):

- ❖ 25–50% of children in this situation will experience some psychological disorder during childhood, adolescence or adulthood, compared to 10–20% of the general population; and
- ❖ 10–14% will be diagnosed with a psychotic illness at some point in their lives, compared with 1–2% of the general population.

Other effects reported included the rates of presentation to a child mental health facility and use of out-of-home care. For example, 42% of children in treatment at an American child mental health facility had a mother with a current diagnosis or history of at least one mental health disorder (84%), and 72% had a father with a diagnosis of, for example, drug abuse, depressive illness or antisocial personality (Hammen et al. 1999, as cited in Farrell et al. 1999). Cuff and Pietsch (1997a) reported findings from overseas studies that at least 30% of children in out-of-home care have a parent with a serious mental illness.

## IMPACT ON CHILDREN AND FAMILIES

Child: My mum is schizophrenic [sic] and she was trying to scare me. When my mum was sick she scared me well . . . How I got to foster care: once I was walking home from school mum told me that ‘these people are going to take you away and I don’t know what to do’. When I got home from school the people came and took me away.

Parent: If only I could clone a ‘well’ version of myself so I could comfort, care for, teach and play with my child when the ‘ill’ version of me is around! (Cowling 1999).

It is well accepted that infants and young children have core needs which must be met to ensure that they develop into normal healthy adults, including love, physical and emotional nourishment, security, protection, stimulation, an appropriate learning environment and socialisation (Kowalenko et al. 1999). Of these, the interactions between the mother and infant are critical to the physical and emotional development of the child.

While many parents who have a mental illness are capable parents, mental health problems can effect parent-child interactions in a variety of ways. For example, parents with depression, when ill, are less able to be affectionate and responsive (Kowalenko et al. 1999), and parents who have schizophrenia may have unusual or inappropriate affective responses to their child (Pope 1998). The impact of the parent’s illness will vary depending on the child’s age when the parent first becomes ill, how severe the illness is, how long it lasts and what alternate family support is available for the child (O’Donovan 1994; McEnroe 1998; Pope 1998; Cowling 1999; and Farrell et al. 1999).

In addition, when a parent is affected by a mental illness, the family is at greater risk of experiencing relationship discord, discontinuity of care, poor general parenting skills, social isolation and poverty and its sequelae, such as poor housing and lack of transport. The mental health of the parent can affect the child from conception—through factors such as drug taking, nutrition and self-harm—through to adulthood (Kowalenko et al. 1999). Such environments, as well as a genetic predisposition to mental illness, can place these children at much greater risk of significantly poorer social, psychological and physical health than other children. The types of difficulties encountered by these children may include (O’Donovan 1994; Cuff & Mildred 1998; Einfeld & McLaughlin 1998; Pope 1998; Cowling 1999; Farrell et al. 1999; Kalucy & Thomas 1999; and Kowalenko et al. 1999):

- ❖ major depression;
- ❖ substance abuse;
- ❖ psychiatric treatment;
- ❖ poor academic performance and learning disabilities;

- ❖ persistent emotional or behavioural disturbance;
- ❖ poor social competence and functioning;
- ❖ involvement with the law;
- ❖ personality disorders;
- ❖ sibling and peer rivalry;
- ❖ feelings of social isolation, inattentiveness and withdrawal;
- ❖ suicide; and
- ❖ post-traumatic stress.

Among infants whose mothers experience mental illness, poor outcomes reported include low birth weight, prematurity, impairments in cognitive and language functioning, physical and psychosocial development.

While there is no doubt that children with parents affected by mental illness have a greater environmental and genetic risk of poor physical, social, emotional and educational outcomes, the impact of their parents' illnesses will vary according to a number of factors. Indeed, there are many children who do appear to successfully negotiate the path to adulthood. In addition, children are generally so resilient that early disadvantage, if corrected, does not necessarily lead to later maladjustment. Mental illness is not homogeneous and can have different effects on parenting skills and different impacts as the children's needs change over time. Risk and resilience factors have been identified as including (O'Donovan 1994; McEnroe 1998; Pope 1998; Cowling 1999; Farrell et al. 1999; and Kowalenko et al. 1999):

- ❖ the onset of parental illness—the earlier the onset, the poorer the outcome for the child;
- ❖ the degree of disturbance owing to the intensity, frequency and duration of the parents' illness;
- ❖ the availability of a healthy alternative caregiver;
- ❖ the degree of family stability or discord;
- ❖ other associated parenting dysfunctions, such as drug abuse or personality disorders; and
- ❖ the degree of rejection or hostility projected onto the child.

Studies have suggested that the risk of the children developing psychopathology can be reduced by interventions that aim to (Cuff & Mildred 1998; Einfeld & McLaughlin 1998, McEnroe 1998; Pope 1998; Farrell et al. 1999; and Kalucy & Thomas 1999):

- ❖ enhance parenting skills—that is, support parents' ability to meet the needs of the children;
- ❖ promote positive child development;
- ❖ reduce parental discord;
- ❖ provide input from other caring adults;
- ❖ improve continuity of care for the children;
- ❖ increase social support and resources, for example prenatal health care, childcare, home visiting and job training;
- ❖ improve children's ability to reality test (assess an ill parent's actions against a more realistic framework), cope and use cognitive problem-solving skills and social support networks; and
- ❖ increase teachers' understanding and responsiveness to the children's social/emotional needs and the effect of a parent's illness on their learning.

Evidence shows that families where a parent has a mental illness can be supported to effectively parent their children, or may not require the support of mental health services at all (Cowling 1999). Keeping families together also has important positive outcomes for the parent who has the mental illness, such as an improvement in mental health after receiving help to manage the stresses of parenting and avoiding the trauma resulting from loss of access to beloved children and a valued parenting role (McGrath & Hearle 1998).

## OPPORTUNITIES FOR MENTAL HEALTH PREVENTION AND PROMOTION

Children with parents affected by mental illness are potentially an easily identifiable high-risk group responsive to preventive interventions and, as such, present a unique opportunity to alleviate suffering and prevent long-term costly social outcomes. There is no doubt that conventions such as the United Nations Convention on the Rights of the Child (1998) require that the needs of these children and their families receive a response, and that a commitment at a policy level exists to do this. A number of prior reports have suggested strategies to do this, and policy frameworks have been developed to inform this approach. These will be discussed in the next section.

## MEETING THE NEED

Many recommendations have arisen from previous work in Australia that has investigated issues at both national and local levels. While different areas of Australia have different mixes of resources and local needs, there are still many similarities in what is seen as an appropriate response to these families. Children live both in their family and the wider community, and their well being is inextricably linked to that of their parents' ability to provide a supportive environment. Thus recommendations address three levels of intervention: the child, their parents and family, and policy and service changes. Summarised below are the themes of previous recommendations from the following reports: (Burdekin, Guilfoyle & Hall 1993; O'Donovan 1994; Cuff & Pietsch 1997a; Shipp 1996; Cuff & Mildred 1998; Einfeld & McLaughlin 1998; Pope 1998; Cowling 1999; Farrell et al. 1999; Kalucy & Thomas 1999; and Kowalenko et al. 1999).

### Support for the child

- ❖ Better care services—for example, continuity of care, especially during parental hospitalisation and non-crisis respite care;
- ❖ Support, for example, from peers, a caring adult or at school;
- ❖ Education regarding mental illness, including heredity, medication, the course of the illness and stigma associated with it;
- ❖ Development of resilience and coping skills, for example social skills, problem-solving skills, and establishing an appropriate role for children, not 'parenting' the parent;
- ❖ Increased community and school-based education and tolerance about mental illness; and
- ❖ Counselling when required.

### Support for the parents (including the non-affected parent) and family

- ❖ Planned care and respite services for children and parents;
- ❖ Validation and support of parenting role, for example peer-support groups, practical home-based training (especially post-hospitalisation), development of parenting skills, and family friendly mental health services;
- ❖ Supportive communities, for example to help to reduce social isolation, assist with links to community resources, and with education of the community regarding mental illness;
- ❖ Family-focused mental health services that, for example, include planning for families' needs, family counselling, ongoing care, and continuity of relationship with a supportive worker;
- ❖ Assistance to link with, and coordinate help with, broader needs, such as housing, health and vocational training;
- ❖ Specialist services where required, such as specialist mother–baby in-patient and day services, and supported accommodation with skill development; and
- ❖ Knowledge regarding mental illness, including about heredity, medication, the course of the illness, and stigma associated with it.

### Policy and service level changes

- ❖ Identification of dependent children, their needs and risk levels by improved intake and assessment procedures and data gathering;
- ❖ Reorientation of services from therapeutic only, to include prevention and a support-based model focusing on long-term responsiveness and wider needs;
- ❖ Professional development and supervisory support for mental health workers to ensure that they can meet the needs of the children and families in a 'best practice' framework, and education for other workers with regard to special issues in service provision for this group, such as considerations for child protection workers when assessing current and future risks to a child's welfare;
- ❖ Investment in culture and attitudinal change to address the assumptions made by workers with regard to the ability of parents who have a mental illness to parent effectively;
- ❖ Coordinated and collaborative interagency service provision from all sectors, including mental health, welfare, education, housing, general practitioners, community support services, drug and alcohol services, family planning, family court and youth justice systems with a view to timely referrals, early intervention and minimising confusion for families;
- ❖ Involvement of consumers in policy development, service planning and staff training; and
- ❖ Service practices, such as acknowledgement of the time required to provide family-oriented services and allocation

of resources to assist this, improved access to mental health services (such as home visiting, assistance with transport or flexible location of services), provision of long-term support congruent with the fluctuating nature of mental illness, and assertive assessment and follow-up.

Suggested strategies to achieve these service-level changes include:

- ❖ a multi-agency focus at all levels of government, including agreements at federal and State levels, and interagency standing committees at regional and State levels;
- ❖ employment of project officers to investigate local needs and resources, and develop strategies and resources to facilitate implementation of best practice management of children with parents affected by mental illness and their families;
- ❖ improved resourcing to enable staff to undertake mental health promotion and preventative activities, as well as to respond to the urgent, more immediate needs of clients; and
- ❖ employment of coordinators with service-development responsibility with respect to the needs of children with parents affected by mental illness.

These service level changes reflect the view expressed by Cowling (1999, p. 44):

It was apparent that the problems arising in attempting to effectively support parents and their children are too complex and the solutions too comprehensive for any one agency or organisation to address on its own. Interagency partnership and collaboration with parents and among services appeared to be one effective way to try and ensure that all children and parents feel that they are fully members of their community.

Previous investigations have also identified a number of obstacles to the implementation of such recommendations. These include the parents' wish to manage on their own and their fear of their parenting coming under scrutiny and subsequently losing custody of their children (Hearle et al. 1999). Service-level obstacles include issues such as no one organisation taking responsibility for leadership in this area and a lack of recognition of the problem coupled with an unwillingness to make this a priority. Difficulties in interagency collaboration are also created by workers' lack of experience and familiarity with this type of service delivery, and confusion created by different understandings of roles, responsibilities and practices (O'Donovan 1994; Cuff & Pietsch 1997a; Shipp 1996; Cuff & Mildred 1998; Einfeld & McLaughlin 1998; Pope 1998; Cowling 1999; Farrell et al. 1999; and Kalucy & Thomas 1999).

Finally, the poor knowledge base about the impact of mental illness on the children and their families, the risk and resilience factors involved, and effective interventions is identified by many reports, with further research being recommended.

## SCOPE OF STUDY

The parameters of the study were as outlined under chapter 1. It was not intended that this study be an exhaustive mapping of all services available for children with parents affected by mental illness. Neither was it within the scope of the project to develop and carry out a research-based methodology. Rather, this study should be viewed as an initial information-seeking activity to provide timely and relevant information to the PPWP on services for these children and families. The methodology used aimed to gather information that was as representative as possible of the true picture of current support and intervention available across Australia.

The methodology included:

- ❖ wide distribution of a questionnaire seeking details of services being provided; and
- ❖ consultations with reference group members across Australia and other groups as described below.

## PROJECT TEAM

A part-time project officer was employed to carry out the project tasks, and national consultation was assisted by the formation of an expert reference group, as well as a broader reference group, which included a number of contacts for wider consultation on particular issues. Contact was maintained through teleconferencing, individual telephone contact and email. Details of the project officer and reference groups are listed in the ‘acknowledgements’.

### Reference group

The role of the reference group was:

- ❖ to provide expert knowledge with regard to the needs and issues related to service provision for children with parents affected by mental illness,
- ❖ to guide the development of project strategies, and
- ❖ to assist with State and Territory-based consultation.

### Broader reference group

The role of the broader reference group was:

- ❖ to provide expert knowledge with regard to the needs and issues related to service provision for children with parents affected by mental illness; and
- ❖ to assist with State and Territory-based consultation.

## METHODOLOGY

### Questionnaire

#### Development

The distribution of a questionnaire was identified as the most cost-effective and time-efficient strategy for collecting national information and data with regard to key projects and services for children of parents with a mental illness, and any future plans for work in this area. The questionnaire was developed in consultation with the reference group and aimed to identify the nature of projects and services for these children, the relevant evidence base on which decisions about these projects and services had been made, how well national mental health promotion and prevention goals had been incorporated, the availability and sustainability of services, and future plans for work in this area (see appendix 2).

#### Distribution

The project team aimed to distribute the questionnaire to:

- ❖ all agencies across Australia, both government and non-government, who were likely to have contact with, or a role in, supporting children, parents and families affected by mental illness, for example adult and child mental health services, child and youth health agencies, departments of family and community services, education departments, family and youth justice services, community support agencies, consumer groups; and
- ❖ any networks, interest groups or agencies specifically identified by the reference group or broader reference group.

Contacts were provided directly by the reference group and the broader reference group, from documents from previous mapping activities (Kraner 1998a and b) and by direct phone contact or Telstra White Pages searches by the project officer for relevant government and non-government agencies. A number of respondents also requested extra copies or indicated that they had distributed an unspecified number of copies via their networks.

The questionnaire was mailed out in a number of stages, accompanied by a covering letter signed by Phil Robinson, chair of the reference group. A reminder letter was mailed to all agencies on 9 December 1999. The latest return date was 15 December 1999, with questionnaires being accepted no later than 23 December 1999. Copies of the questionnaire and cover letter were also distributed electronically via the general practitioner email ListServe.

### Data entry and analysis

The questionnaires were coded by the project officer and entered into Excel 97 by a typist, with each entry visually checked by the project officer. Data was analysed using Access 97.

### Consultations

Consultations were carried out with the reference group via whole group teleconferences and individual phone or email contact for particular issues, for example State-specific information, or areas of specific expertise.

The Western Australian group, Interagency Collaboration for Children of Parents with Mental Illness (ICCOPMI), participated in a one-hour telephone consultation with Phil Robinson and Sue McAllister on 27 January 2000. The study was described and preliminary findings were outlined, and there was an opportunity to discuss the issues these practitioners encountered in service provision to parents and their children.

The project officer and chair of the reference group presented preliminary findings and attended the South Australian forum convened to discuss the needs of children and young relatives of people with mental illness on 18 February 2000.

Draft findings and recommendations were presented to the PPWP on 3 February 2000 for discussion and feedback. Recommendations were finalised in July 2000 and the report was completed by August 2000, after subsequent consultation with the federal Department of Health and Aged Care.

As described in the Methodology section, information was gathered by the scoping study in a number of ways. The findings of these information-gathering strategies are organised in the following manner:

- ❖ ‘State synopses’ contains a brief synopsis of the situation regarding services in each State;
- ❖ ‘Questionnaires’ contains analyses of questionnaires with regard to the overall picture of services, followed by a more detailed analysis of specific programs designed to directly or indirectly assist children with parents affected by mental illness (appendix 3 also contains some supplementary results); and
- ❖ ‘Consultations’ contains information arising from consultations.

Summaries of the programs are included in appendix 4.

### STATE SYNOPSES

Specific service provision for children with parents affected by mental illness is a very new area of activity. Initial concerns regarding the lack of support for these children and their families were raised in Burdekin et al. (1993), *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*. Federal policy initiatives such as the Second National Mental Health Plan: 1998–2003 (1999), and the MHPP National Action Plan (1999) (see chapter 8 and appendix 5), represent a response to these concerns. The States and Territories have subsequently responded to this leadership from the Federal Government in a number of ways.

#### Australian Capital Territory

Information was not available at the time of the study.

#### New South Wales

Mental health services in New South Wales have a well-documented orientation towards prevention, promotion and early intervention for mental health problems, with an emphasis on partnerships with other services and organisations to implement programs (see policy documents and summaries from the Centre for Mental Health, New South Wales, in chapter 8 and appendix 5). Children from families affected by mental health problems are one specific focus areas for these activities.

The New South Wales Centre for Mental Health Prevention Unit acknowledges that prevention, promotion and early intervention are relatively new fields in mental health, and aims to develop services in these areas through:

- ❖ training and educating mental health and related staff and community members in relevant knowledge and skills;
- ❖ providing leadership (through strategies, frameworks and statewide committees); and
- ❖ providing resources (materials, information sessions and networks) to assist with implementation of services.

Specific goals for assisting children of parents affected by mental illness include working with AMH workers to enhance their ability to provide family-focused care to clients who have children. It is acknowledged that systems are needed to identify clients who have children to ensure that the following strategies can then be developed and implemented:

- ❖ establishing a plan for crisis responses for families when a parent is admitted to hospital or can't care for children;
- ❖ screening children to identify those at risk from environmental or genetic factors;
- ❖ developing a resource kit to help AMH workers provide families with information on mental health issues; and
- ❖ establishing support groups for parents, children and young people.

Each area health service has a project officer supported by the area child and adolescent mental health coordinator, who focuses on the needs of children with parents affected by mental illness. These positions are unofficially designated as Children of Parents Suffering Mental Illness (COPSMI) project officers and have implemented different strategies according to the priorities of the area health service with which they are working, for example direct service provision, literature searches or education of staff.

## Northern Territory

In total four questionnaire responses were received from the Northern Territory, and none indicated that they were providing a specific program related to this client group; however, one mentioned plans for work in this area in the future. Discussion with Marco Klobas, Policy Officer, Mental Health, Territory Health Services, Northern Territory, indicated that the agency was aware of the particular needs of this group and will address them when an appropriate strategy is identified and resources available. However, the small population size of the Northern Territory, distributed over a large geographical area and including a large number of Indigenous people, results in particular difficulties in establishing such initiatives. For example, peer support for children is sometimes difficult to achieve in isolated locations and culturally appropriate interventions require specific resources and training. Workers have a general awareness of the specific issues and needs of these families.

## Queensland

Queensland Health's Future Directions for Child and Youth Mental Health Services: Queensland Mental Health Policy Statement, published in 1996, identifies children living with family members who have a mental illness as being at high risk of developing serious mental health problems and disorders. Mental health prevention, promotion and early intervention concepts do not receive a great deal of attention in this policy document, but this is probably owing to the age of the document relative to policy documents from other States. Overall, there is relatively little activity directed at supporting these children and their families, with two of the 48 responses from Queensland classified as being for children and families with a mentally ill parent. Only 11 of the remaining 46 responses indicated that they had plans for work in this area in future.

However, it is encouraging to note that, in 1996, the Queensland Centre for Schizophrenia Research, with funding support from the Queensland Health Promotion Council, began a ten-year program of research into the needs of parents who have a mental illness. Initial research was reported in May 1998, and included detailed information about a number of service-related recommendations, for example funding for a project officer to develop services, and for an interagency steering committee to investigate service planning and development to meet the needs of parents with serious mental illnesses. Comments by respondents and personal correspondence with Queensland services indicated that such services were under consideration in some areas. For example, a district multi-agency working party, based at the Royal Children's Hospital Health District, has recently been formed to organise a response to the needs of children with parents affected by mental illness.

## South Australia

In 1997 the Strategic Plan for the Purchasing of Mental Health Services for Children and Young People (Draft) established that children of parents with a mental illness require services to be developed and delivered in specific ways. Various local initiatives began in South Australia in 1997; however, there was no comprehensive approach to this specific area until the MHPP National Action Plan (1999) document was launched, which provided an opportunity for focusing on specific population groups.

The State Mental Health Unit, Department of Human Services has been active in providing leadership in this area by linking consumers, carers and bureaucrats to plan a more strategic statewide response. A forum was held in Adelaide on 18 February 2000 to discuss the needs of children and young relatives of people with mental illness. This stakeholder forum was convened by consumers, carers, non-government organisations and the Mental Health Unit, and invited representatives from these areas as well as the adult and child mental health sectors. The objectives of this forum were to confirm current supports available, to identify service gaps, to provide an opportunity to discuss needs, and to develop a discussion paper to inform the Department of Human Services policy and strategy for this group. It is promising that eight out of the 16 questionnaire responses from this State indicated that future plans to meet the needs of these children and their families were under consideration.

A draft policy is currently with stakeholder groups as part of a consultation process. Six key areas have been established for short, medium and long-term attention. These are:

1. the development of a range of resources and information for the community and specifically for children of parents with a mental illness;
2. better cooperation between AMH and child and adolescent mental health services (CAMHS);

3. capacity building, training and staff development;
4. partnerships with and encouragement for consumer organisations;
5. codes of practice and quality standards; and
6. local support groups and initiatives.

At the forum a new non-government organisation was formed called Children of Mentally Ill Consumers (COMIC), and two members of this forum attended the recent workshop in Melbourne presented by the National Network of Adult and Adolescent Children Who Have a Mentally Ill Parent/s Inc (NNAAMI) on behalf of the Department of Human Services.

## Tasmania

Tasmania is also in the early stages of developing plans to meet the needs of children and parents in situations where a parent is mentally ill. The Tasmanian Department of Health and Human Services' Mental Health Services in Tasmania: A Plan for Now and the Future—Strategic Plan for 1999–2002 (1999), includes 'an increased focus on promotion and prevention' (p. 7). The policy includes a number of strategies relevant to families with a mentally ill parent under goals related to promotion and prevention of mental health, and reducing the impact of mental disorder on individuals, families and the community.

The recent publication of Farrell et al. 1999, *Tasmanian Children's Project Report: The Needs of Children and Adolescents with a Parent/Carer with a Mental Illness*, which provides detailed information on this client group, will no doubt form an integral part of this State's service planning. However, currently only two of the 27 respondents to the questionnaire from Tasmania indicated future plans for this client group. Nevertheless, consultations indicate that service providers are aware of the needs of these clients (see Farrell et al. 1999), but feel powerless or under-resourced to meet this need.

## Victoria

The Mental Health Branch of the Victorian Department of Human Services has published a number of policy documents as guidelines for regional planning for providing quality mental health care, and include a focus on promotion, prevention and early intervention (see chapter 8 and appendix 5). A number of these documents specifically mention children and their parents, where a parent has a mental illness. These include the document *Victoria's Mental Health Services: The Framework for Service Delivery, Child and Adolescent Services* (1998), and subsequent papers looking at strategies to implement the policy direction espoused in that document.

Activities in Victoria, and in fact Tasmania and Queensland, have been facilitated enormously by two projects conducted over four years funded by the Victorian Health Promotion Foundation. A three-year research project in 1993-96, called *Children of Parents Experiencing Major Mental Illness*, was conducted by the Early Psychosis Research Centre, Department of Psychiatry, University of Melbourne. Work from this project has informed subsequent research in Australia in, for example, Queensland (Hearle et al. 1999) and Tasmania (Farrell et al. 1999).

The second project, the *Southern Partnership Project—Interagency Collaboration to Effectively Meet the Needs of Families with Dependent Children where Parents Have a Mental Illness*, followed immediately in 1996-97, and was based on this research. This mental health promotion project developed important links between agencies and interagency protocols across four different localities in the southern metropolitan region of Melbourne. In addition, the *CHildren And their Mentally ill ParentS* (CHAMPS) project (March 1995 – June 1997) was also based on the above research and funded by national mental health funding from the Mental Health Branch of the federal Department of Health and Aged Care. This project resulted in a range of initiatives including:

- ❖ the Working Together project, which aimed to develop a framework for the creation of interventions, developing best practice principles for service provision and interagency collaboration; and
- ❖ peer-support intervention programs for children.

Many of the projects currently running in Victoria acknowledge these initiatives as forming the basis for the development of their programs and activities. A further indication of the relatively high level of activity, and subsequent development of knowledge and expertise in Victoria since 1994, is the publication in 1999 of *Children of Parents with Mental Illness*, edited by Vicki Cowling, and incorporating contributions from children, parents and

service providers in Victoria.

## Western Australia

Information was not available at the time of the study with regard to the mental health policy background to supporting children whose parents have a mental illness. However, in addition to the five programs already specifically targeting this client group, a large number of workers from a range of metropolitan and country government and non-government sectors participate in ICCOPMI. This community development collective has been meeting monthly for just over two years to identify issues and strategies regarding this client group.

This group arranged a highly successful seminar during Mental Health Week in November 1999, in collaboration with consumers, to raise awareness and educate workers about the issues and needs of this client group. Such activities reflect an increasing awareness of the particular needs of these children and their families, as does the fact that 20 out of the 55 questionnaire respondents from this State indicated that they were considering future plans to meet these clients' needs.

## QUESTIONNAIRES

### All questionnaires

Owing to the distribution strategies used, it is difficult to determine exactly how many people or agencies received questionnaires. However, the initial mail-out was of the order of 566 questionnaires, which would represent the minimum number of questionnaires received by people or service agencies. A total of 223 questionnaires were returned by 24 December and were analysed. The analysis is summarised below with further detail included in appendix 3.

The first questions in the questionnaire asked respondents to indicate whether their organisation was currently providing a program that directly or indirectly addresses the needs of children under the age of 18 whose parents have a mental illness. Of those questionnaires that were returned (N=223), six gave no response to this question, 108 said they were providing a program and 109 said they weren't. Responses were received from all States and Territories except the Australian Capital Territory. Despite the questionnaire's wide distribution, non-mental health agencies were poorly represented among respondents, including, for example, departments of education, family and youth services, justice agencies (such as family court, youth justice and correctional services agencies), and child and youth health services.

However, further examination of programs being provided indicated that the data required more detailed categorisation to identify programs that were specifically targeted to children with parents affected by mental illness. Many organisations indicated that these children or their parents may incidentally receive services from them, rather than having services specifically targeted to, or tailored for, their particular needs. The following categories were developed, and the returned questionnaires were coded into one of these categories.

### Program type

Programs were classified into the following types:

1. No program and no future plans.
2. No program but had future plans of a general nature to meet the needs of this client group, but did not complete the rest of the questionnaire. For example, a response on a questionnaire in this category said, 'Upon regionalisation and appointment of a mental health manager we will address this issue'.
3. No program but had specific future plans to meet the needs of this client group, but did not complete the rest of the questionnaire. For example, a response on a questionnaire in this category said, 'Currently we have a working party developing more specific interventions for this group over the next 12 months'.
4. Mental health program providing support, that is parental mental illness may be a factor, but no specific programs to meet the particular needs of this group. For example, a child and adolescent mental health service, which identified itself as meeting the needs of this client group, filled out the questionnaire indicating that children with parents affected by mental illness were among the clients seen by the service, but did not describe a specific program or strategies to address these clients' particular needs.

5. Program with general support to parents, families and children where parental mental illness may be a factor, for example a parenting program for at-risk families, which may be attended by some parents affected by mental illness.
6. Postnatal mental health program, for example an in-patient facility for mothers and infants experiencing postnatal stress.
7. Programs specifically designed to meet the needs of children with parents affected by mental illness, including:
  - { research;
  - { policy development;
  - { education of professionals;
  - { education of the community; and
  - { specific programs related to service delivery.

Note that programs that addressed children's or parents' needs indirectly were included in category 7, for example research, policy development and education, and parenting groups specifically for parents who have a mental illness.

Table 1: Classification of responses

Type of program	Number of programs	Percentage of total responses
1. No program	100	44.8%
2. No program but general future plans	13	5.8%
3. No program but specific future plans	7	3.1%
4. Mental health program	34	15.3%
5. General community program	12	5.4%
6. Antenatal program	13	5.8%
Subtotal	179	80.2%
7. Specific programs		
Research	2	0.9%
Policy development	3	1.3%
Education professionals	4	1.8%
Education community	1	0.5%
Specific program	34	15.3%
Subtotal	44	19.8%
Total number of responses	223	100%

Of the organisations not currently providing a specific program (categories 1 to 6), 17 respondents made comments indicating an awareness of the particular needs of this client group, for example they referred clients to other agencies for related services such as parenting courses, or gave children in these families a higher priority on the waiting list. Six respondents clearly indicated that funding was a barrier to providing services such that preventative and promotional activities could not be undertaken. They said, for example, 'We are funded to work directly with the person with the mental illness', 'To commence services in this area is part of our strategic plan. However it is resource dependent. Therefore it waits'.

Of those services classified in category 7, the majority (34, or 77.3% of programs in this category) provided a program designed to address the specific issues related to children with parents affected by mental illness. Of these, six addressed service provision initiatives, for example better identification of AMH clients who were parents, and collaborative forums. Twenty-eight provided direct intervention for these children or their parents, with some of these also addressing service-related issues.

Table 2: Numbers of programs in each State specifically targeted at children or parents with a mental illness/mental health problem

State	Number of programs
NSW	13
Qld.	2
SA	4

Tas.	2
Vic.	18
WA	5
ACT	0
NT	0
Total	44

## Future plans

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Overall 75 (33.6%) of the questionnaires returned indicated that the respondents did have future plans to provide services for these clients. Eighty-four (37.7%) indicated that they did not (or gave a response subsequently classified as such, for example ‘We are funded to work directly with the person with the mental illness’) and 64 (28.7%) did not respond to this question (see table 3 for a further breakdown of responses). Queensland and Tasmania had a particularly low proportion of future plans, and Western Australia and the Northern Territory also had few future plans relative to the remaining three States (see table A1, appendix 3).

Of those services that responded to the questionnaire indicating that they did not provide a program for this client group and have no future plans to do so (N=100), 26 services were readily identifiable as a child, adult or community mental health service.

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The majority (59.1%, N=29) of those services already providing programs targeted to this client group had future plans. These related to expansion of both client-related strategies and initiatives aimed at improving service provision to complement existing programs, for example running a parent program to complement the peer program already provided to children, and developing policy and protocols. The need to secure future funding for continuation of programs was indicated by two programs.

Table 3: Future plans to provide or modify programs for children with parents affected by mental illness

Type of program	Future plans?		
	Yes % (N)	No % (N)	No response % (N)
No program (N= 120)	16.7% (20)	83.3% (100)	0
Mental health service (N= 34)	35.3% (12)	8.8% (3)	55.9% (19)
General community program (N= 12)	41.7% (5)	25.0% (3)	33.3% (4)
Antenatal program (N= 13)	46.1% (6)	7.8% (1)	46.1% (6)
Programs specifically for children with parents affected by mental illness (N= 44)	59.1% (26)	2.3% (1)	38.6% (17)

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## Analysis of specific programs

The following results pertain to the 44 programs (or subsets of these) that provided services specifically targeted to children or their parents when at least one parent is mentally ill. See appendix 4 for summaries of these programs. Postnatal programs were excluded from this analysis for several reasons: parents utilising these programs may or may not have a specific mental illness, and a detailed examination of these programs is included in The Perinatal and 0 to 2 Scoping Project (AICAFMHA 2000).

## National priority mental health targets

A number of national priority mental health targets were identified as pertaining to children with parents affected by mental illness, and respondents were asked to indicate any that applied to their program.

Table 4: National priority mental health targets addressed by the programs

National priority mental health target addressed	Yes % (N)	No % (N)	No response % (N)
Promote optimism, resilience, and social and emotional well-being for children whose parents have mental health problems and disorders	81.8% (35)	4.6% (2)	13.6% (6)
Engage families where one or both parents have a mental illness in mental health promotion and prevention programs	54.6% (24)	31.8% (13)	13.6% (6)
Reduce the impact of risk factors on the mental health of all family members	72.8% (32)	13.6% (6)	13.6% (6)
Enhance parenting skills, child development and family functioning	68.2% (30)	18.2% (7)	13.6% (6)
Promote strong and positive attachments between parent and child	63.7% (28)	22.7% (10)	13.6% (6)
Promote child and family participation in school and community activities	40.9% (18)	45.5% (20)	13.6% (6)
Other	6.8% (3)	79.6% (35)	13.6% (6)

Other areas that were identified as targets by respondents included:

- ❖ mental health promotion/prevention generally. Reduces stigma, enhances mental health awareness and literacy, provides information on local resources in the community, encourages seeking help early;
- ❖ through family counselling; and
- ❖ support for workers enhancing services to this target population.

## Direct client service strategies used

A number of strategies were identified by the project team as appropriate to meet the needs of children with parents affected by mental illness. These included service provision directly to clients, as well as initiatives to improve service response to this client group.

Only those programs that provide an intervention directly to children or parents (28 of the 34 programs were identified as targeting issues specific to this client group) were analysed, as opposed to research, education, policy development or service initiatives. These strategies are itemised in table 5. See appendix 3 for a State-by-State breakdown of strategies.

Table 5: Client strategies used by programs

Strategy used (ranked in order of frequency)	Yes % (N)	No % (N)	No response % (N)
Education on mental illness for children with a mentally ill parent	82.1% (23)	14.3% (4)	3.6% (1)
Individual counselling regarding issues arising from having a parent with a mental illness	64.3% (18)	32.1% (9)	3.6% (1)
Education on child development for parents who have a mental illness	60.7% (17)	35.7% (10)	3.6% (1)
Individual counselling regarding parenting issues with parents who have a mental illness	57.1% (16)	39.3% (11)	3.6% (1)
Support groups for the children whose parents have a mental illness	50.0% (14)	46.4% (13)	3.6% (1)
Support groups for parents who have a mental illness	39.3% (11)	57.1% (16)	3.6% (1)
Camps for children and/or their parents	39.3% (11)	57.1% (16)	3.6% (1)
Home-based support	35.7% (10)	60.7% (17)	3.6% (1)
Supported accommodation for families where a parent has a mental illness	10.7% (3)	85.7% (24)	3.6% (1)
Respite care for families where a parent has a mental illness	17.8% (5)	78.6% (22)	3.6% (1)

Fourteen mental health agencies who stated that they were not offering a program for children with parents affected by mental illness (category 4) indicated that they were involved in providing these types of client strategies. As this was contradictory, the questionnaires were examined further, and it appeared that these items were selected if children or parents were participating in activities where the mental illness or parenting was not necessarily the focus, for example parenting groups run by mental health agencies and social support groups for people with a mental illness. Some agencies also indicated that they were offering these types of programs, when in fact they were referring children or parents requiring this type of intervention to other programs.

### Service delivery initiatives

Initiatives to improve service responses to this client group were identified by the project team and examined in relation to programs (category 7) classified as specifically targeting the needs of children and parents where at least one parent is mentally ill (table 6). All but one of these programs either indicated that they applied one or more service strategies or did not respond to this question. One program, a community education program, indicated that it did not use any of the service strategies listed.

Two comments relevant to the question were made under 'other':

- ❖ Help existing services work together; and
- ❖ All of the above objectives are appropriate to the program, but achieved through Health Professional Education.

Responses examined on a State-by-State basis indicate that, where four or more programs exist, responses were fairly evenly spread across each service-delivery initiative.

Table 6: Service delivery initiatives used by programs

Service strategies used (ranked in order of frequency)	Yes % (N)	No % (N)	No response % (N)
Education of staff regarding the needs of children whose parents have a mental illness	72.8% (32)	13.6% (6)	13.6% (6)
Establishment of interagency networks of professionals sharing ideas and strategies	70.5% (31)	15.9% (7)	13.6% (6)
Establishment of best practice principles to ensure appropriate service response to the needs of children whose parents have a mental illness	59.1% (26)	27.3% (12)	13.6% (6)
Service initiatives to improve the identification of adults who have a mental illness who are also parents	54.6% (24)	31.8% (14)	13.6% (6)
Advocacy for children whose parents have a mental illness	54.6% (24)	31.8% (14)	13.6% (6)
Other	6.8% (3)	79.6% (35)	13.6% (6)

A number of mental health agencies indicated that they were not providing a program specific to children with parents affected by mental illness but still selected items indicating that they were involved in service strategies targeted at this client group. As organisations may not have identified these activities as a specific ‘program’, but may in fact be meaningfully involved in indirectly improving service response to these children and their families, this information has been included in table 7.

Table 7: Service strategies used by mental health programs not providing a specific program

Service strategies used	Yes % (N)	No % (N)	No response % (N)
Service initiatives to improve the identification of adults who have a mental illness who are also parents.	41.2% (14)	52.9% (18)	5.9% (2)
Establishment of best practice principles to ensure appropriate service response to the needs of children whose parents have a mental illness	44.1% (15)	50.0% (17)	5.9% (2)
Education of staff regarding the needs of children whose parents have a mental illness	44.1% (15)	50.0% (17)	5.9% (2)
Establishment of interagency networks of professionals sharing ideas/strategies	64.7% (22)	29.4% (10)	5.9% (2)
Advocacy for children whose parents have a mental illness	35.3% (12)	58.8% (20)	5.9% (2)
Other	2.9% (1)	91.2% (31)	5.9% (2)

### Additional strategies

Organisations identified 23 strategies that they felt were not covered under the options offered in previous questions about what types of strategies were used directly with clients and what types of service-improvement initiatives were targeted at this client group. This included education aimed at increasing workers’ understanding of other services available to their clients, for example in-service programs such as those presented to ward staff by community-based bodies about their services and vice versa, and agency visits. Development of staff skills and knowledge included strategies such as cofacilitation of current groups with a more experienced staff person. Development or use of resources such as books, videos, program kits and newsletters or flyers was mentioned, as well as creating child-friendly areas in wards or AMH services. Further client-related strategies included an ongoing drop-in program offering continuing support to children, family counselling and family camps.

## National mental health outcomes

Organisations were asked to identify which outcomes identified by the MHPP National Action Plan (1999) were addressed by their program (see table 8 for responses). Comments in the ‘other’ category included identifying that these mental health outcomes were being indirectly addressed through supporting the parents, or indicating that peer support, improved resiliency, or improving general social or emotional health for the children were also mental health outcomes.

Table 8: Mental health outcomes addressed by programs

Mental health outcome	Yes	No	No response
Improved support for children whose parents have a mental illness	75.0% (33)	11.4% (5)	13.6% (6)
Improved mental health among children whose parents have a mental illness	65.9% (29)	20.5% (9)	13.6% (6)
Increased knowledge and understanding by the children of their parent’s mental illness and available mental health services for their parents	63.7% (28)	22.7% (10)	13.6% (6)
Reduced feelings of stigma amongst children whose parents have a mental illness	68.2% (30)	18.2% (8)	13.6% (6)
Other	31.8% (14)	54.6% (24)	13.6% (6)

## Interagency collaboration

Respondents were asked to indicate what degree of interagency collaboration was involved in their program on a 0 to 4 point scale, 0 representing ‘none/minimal’ and 4 representing ‘extensive’ (table 10). The majority of programs (59.1%, N=26) indicated that ensuring the needs of children are met was the focus of collaboration, for example interagency case discussion. Improving the identification of children with parents affected by mental illness was the focus of 44.5% (N=20) of interagency collaborations. Overall, 34.1% (N=15) of programs indicated that the interagency collaboration was focused on both goals.

The types of agencies involved in collaborations are described in table 9. The number of agencies involved varied from one to 19. Of the 37 programs that indicated they were involved in interagency collaboration, 13 collaborated with between one and four other agencies, and 18 collaborated with five to eight agencies. Four programs collaborated with nine, ten, 17 or 19 agencies respectively.

Collaborative activities included joint provision or funding of programs, or provision of venues and multi-agency steering committees for particular projects. Many collaborative ventures consisted of interagency meetings to enable information/resource sharing, education and collaborative service provision, and joint case consultations.

Table 9: Types of agencies with which programs collaborated

Types of agencies collaborated with	Number collaborating with these agencies
Child and adolescent mental health services	63.6% (28)
Adult mental health services	70.4% (31)
Legal services	4.5% (2)
Child and youth health services	34.1% (15)
Welfare services	47.7% (21)
Schools	40.9% (18)
Childcare	25.0% (11)
Foster care/alternative care services	34.1% (15)
Maternal and child health services	34.1% (15)
Child protection services	50.0% (22)
Other	22.7% (10)

Table 10: Degree of interagency collaboration

Area	Degree of collaboration				
	0 (none/minimal)	1	2	3	4 (extensive)
Nationally	7 (15.9%)	5 (11.4%)	6 (13.6%)	10 (22.7%)	16 (36.4%)

### Target group

Respondents were asked to indicate which age group was the target for their program (see appendix 3, tables A4 and A5). Most programs indicated a number of age groups, with only six programs indicating one age group. Most (18) indicated two or three age groups, with 11 indicating four or more age groups. Nine programs either did not respond or were unclear in their response.

Program descriptions indicated that many programs were involved in a combination of strategies related to supporting parents who have a mental illness, children living with a parent who has a mental illness, education or research about these issues, or service improvement initiatives. Some programs were not described or their descriptions were a little unclear; however, it appeared that at least 13 included components directed at the children themselves, 13 at the parents, ten at service initiatives, three in educative activities and one in research.

### Reach of program

Organisations were asked to indicate whether their program was local, regional, statewide or national. There were so few programs in each State that it is clear that the majority of the population across Australia does not have access to specialist support if required; this was particularly true of areas outside capital cities.

Table 11: Reach of program

<u>Reach of program</u>	<u>Percentage (N)*</u>
Local	47.7% (21)
Regional	38.6% (17)
Statewide	11.4% (5)
National	4.5% (2)
No response	13.6% (6)

\* a number identified themselves as having several areas of influence, so the total will be greater than N=44.

### Level of research evidence

Organisations were asked to indicate the types of research evidence that underpin the design of their program, using the National Health and Medical Research Council's (NHMRC) levels of evidence as response categories. The content of 'other' responses was varied. Some indicated that program evaluation information was being used, for example that of other programs previously used in Australia and described in Cowling (1999). Others were relying on the experiences of other practitioners, which may not have been formally evaluated. Some responses indicated that service providers were not differentiating between program evaluation of their own program and the evidence base underpinning their program. The need for resources to critically examine the literature was also mentioned, and there was as an indication that, where literature had been read, a critical analysis of the level of evidence had not been undertaken.

Overall, 29 programs did not indicate any level of research evidence, and the remaining 15 programs did not indicate more than two levels of evidence (see table 12).

Table 12: Level of research evidence underpinning programs

Research evidence	Yes	No	No response
A systematic review of all relevant randomised controlled trials	6.8% (3)	75.0% (33)	18.2% (8)
Evidence obtained from at least one randomised controlled trial	2.3% (1)	79.5% (35)	18.2% (8)
Evidence obtained from well-designed pseudo-randomised controlled trials	4.5% (2)	77.3% (33)	18.2% (8)
Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group	6.8% (3)	75.0% (33)	18.2% (8)
Evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series with a parallel control group	0	81.8% (36)	18.2% (8)
Evidence obtained from case series, either post-test, or pre-test and post-test	29.5% (13)	52.3% (23)	18.2% (8)
Other (please specify and cite references where applicable)	27.3% (12)	54.5% (24)	18.2% (8)

Table 13: Numbers of levels of research evidence indicated

Level of research evidence indicated	Number of programs
None indicated, but a comment under 'other'	16
None indicated	5
No response	8
One level of evidence	8
Two levels of evidence	7

### Program evaluation

Thirty (68.2%) of the programs included an evaluation component, with seven (15.9%) indicating that evaluation was not being undertaken and a further seven (15.9%) not responding to this question. None of the evaluations included a control group. Of those using an evaluation strategy, eight used one strategy only, 17 used two strategies, four used three strategies and one program indicated that they used all five strategies listed. A number of comments were made to add further information on the design of follow-up strategies, for example the period of time over which follow-up occurred and indicating that the evaluation was external. One comment appeared to describe a consumer satisfaction survey: 'students return evaluation forms at the end of the talk', but the respondent did not tick that item on the questionnaire, so 31 programs could be described as including an evaluation component.

Respondents were also asked to describe any other evidence of program effectiveness. The majority of answers to this question provided more detail on the results of program evaluation strategies.

Table 14: Program evaluation strategies used

Evaluation strategy (in order of frequency of use)	Yes	No	No response
Consumer satisfaction survey	50.0% (22)	22.7% (10)	27.3% (12)
Program specific before and after program measures	29.5% (13)	43.2% (19)	27.3% (12)
Standardised or published before and after program measures	18.2% (8)	54.5% (24)	27.3% (12)
Focus groups	18.2% (8)	54.5% (24)	27.3% (12)
Trend analysis of existing data (for example, referral rates before and after intervention)	15.9% (7)	56.8% (25)	27.3% (12)
Other	15.9% (7)	56.8% (25)	27.3% (12)

## Consumer involvement

Thirty-four programs mentioned involvement of consumers in programs to directly or indirectly support children with parents affected by mental illness. The nature of involvement varied from direct involvement, such as in the design and delivery of a program (six programs), to consultation (25 programs) regarding its content, participation in evaluation or representation on the project advisory group or committee. Three responses were unclear, and ten programs did not respond to this question. Eight of those programs involving or consulting with consumers specifically mentioned that young people living with a mentally ill parent were involved.

## Funding

State Governments funded the majority of programs (61.4%, N=27), and many were run within existing service allocations—that is, no special funding was provided to support the program. The Federal Government was the next most common funding body (9.1% or 6 programs), followed by non-government bodies (4.6%, N=2), and a private body and local government (2.3%, N=1 respectively).

## CONSULTATIONS

The project reference group was consulted as a group via teleconferences, as well as through many individual consultations, about, for example, feedback on the format of the questionnaire, and feedback regarding the content of the report prior to its presentation to the PPWP. All consultations were incorporated into the methodology used by the scoping study and included in the content of the final report.

## ICCOPMI

Consultation with the Western Australian ICCOPMI group on 27 January 2000 identified a number of themes or issues. These included issues such as these:

Whose clients are these children?

- ❖ Who is the focus of the intervention and who is responsible for them, for example many parents have dual diagnoses and some families may have multiple needs, so more than one program or agency may be involved.
- ❖ There is no clear direction from the State mental health agency about who is responsible for case management.
- ❖ The children are ‘ghosts’, that is they often don’t register at a service level, may not be identified, and if they are, often cannot be counted.

How can agencies provide a multisystemic approach and provide a network of support?

- ❖ The stigma attached to mental illness results in generic agencies backing off from parents and families when they realise that mental illness is a significant factor within the family.

- ❖ Services are outsourced, fragmented and underfunded, with gaps created by definitions of who is responsible for the child or parent.
- ❖ The time required for collaborative work is high.
- ❖ The time needed for, and cost of, training staff is high.

How should programs meet needs effectively—that is, how can they provide intervention and support that is flexible and not time limited?

Programs need to be reoriented from cure to prevention.

How will prevention and promotion work occur when funding is based on numbers of people seen, not even on how often each person is seen?

## Presentation of draft report and recommendations to PPWP

The draft report and recommendations were circulated to the PPWP and presented for discussion by Phil Robinson, chair of the reference group, at the PPWP meeting on 3 February 2000. This discussion was important for further development of the recommendations.

## South Australian Forum on Children and Young Relatives of People with Mental Illness

On 18 February 2000, the project officer and chair of the reference group attended the South Australian forum convened to discuss the needs of, and to develop a policy and strategic priorities for, children and young relatives of people with mental illness. Preliminary results of the scoping project were presented, and the project officer and chair participated in discussion groups.

The aims of the forum were to:

- ❖ establish the principle needs of children of parents with a mental illness from a consumer perspective;
- ❖ develop a Department of Human Services policy concerning children of parents with a mental illness; and
- ❖ confirm appropriate short, medium and long-term strategic priorities to meet the needs of this group across South Australia, including specific strategies for rural regions.

Points raised strongly confirmed the content and recommendations of the scoping project.

A draft policy paper was prepared following the forum and is currently under consultation. Consumers are planning a follow-up forum.

## Federal Department of Health and Aged Care

Consultations from February to July 2000 with the federal Department of Health and Aged Care have assisted in refining the content and recommendations of the scoping project.

### OVERVIEW

This scoping study is intended to be an initial information-gathering inquiry into services in Australia for children with parents affected by mental illness. A great deal of useful information was gathered and it will provide a basis for raising a number of issues for future consideration and action. A detailed description of the data collected by the questionnaire is included in the Results section of this report (chapter 4), along with summaries of consultations carried out. Further information on each program that responded can be found in appendix 4, and resource information is included in chapter 8 and appendix 5. A brief discussion of issues arising from both the data collected by the questionnaire and those raised through consultations follows.

The scoping study has been very successful in gathering a great deal of relevant information and identifying issues that require attention. A number of constraints arose because of the methodology used and the need to supply information to the PPWP in a timely fashion. Thus this cannot be considered to be a rigorous research project, rather it is an initial examination of a newly developing area of knowledge and practice. As this was not a mapping exercise, a number of relevant programs and activities may not have been identified. Opportunities for consultation and discussion with consumers and practitioners regarding the issues around children with parents affected by a mental illness and their families were utilised wherever possible, but funding did not allow for a thorough consultative process.

Notwithstanding these considerations, a significant amount of useful information was gathered, a number of issues were highlighted and conclusions were reached.

### Scarcity of programs

The States and Territories are, not surprisingly, at different developmental stages in meeting the needs of this group, varying from emerging awareness through to a small but dynamic group of programs and activities that target the strategies currently understood as being most effective. Most have policy frameworks in place that form an excellent starting point for future work and appear to have supported a number of newly emerging initiatives.

It was encouraging to see that many States have started collaborative, consultative or research processes with a view to identifying the issues for these children and their families and their appropriate local responses. South Australia has almost completed development of a policy specifically addressing mental health services responses to the needs of these children and their parents. Western Australia has a large and active interagency group collaborating on raising awareness of the needs of these children across the State. Tasmania has recently completed a research project that identifies these children and their needs, which will inform that State's response. Queensland has an active research program, run through the Queensland Centre for Schizophrenia Research, investigating the needs of parents who have a mental illness.

Many mental health agencies are involved in establishing interagency networks of professionals sharing ideas and strategies (67.7%), and around 40% are involved in other service-related initiatives that would improve their responses to these families (see table 7). Also, many responses indicated an emerging awareness of the particular needs of children with parents affected by a mental illness, as indicated by 33.6% of all respondents stating that they had some future plans for services in this area. Thus leadership in policy development at a state and federal level appears to be having a significant effect at the service-delivery level.

In terms of programs that respond to the specific needs of these children and their parents, or specific strategies to facilitate an effective response from mental health services to these families, Victoria and New South Wales are further developed than other States. It would appear that activities in Victoria have been given particular impetus by an initial research study funded by the Victorian Health Promotion Foundation in 1993, followed by the commitment of project participants to very active dissemination of the resulting information across the State, and in fact nationally. The subsequent piloting of direct service delivery programs funded by the Commonwealth, such as peer and parent support by the CHAMPS program, has added to this momentum.

As this area of practice is still a relatively new one in Australia, there continue to be many gaps in the availability of

services, even in Victoria. Overall there are only 50 programs (44 were identified in time for inclusion in the study) nationwide that offer interventions specifically tailored to the particular needs of both these children and their parents. Of these 44 analysed, only 21 are able to provide support directly to the child. However, the commitment to consultation, networking and sharing expertise is evident across all States, and will assist the future development of all such programs.

Although this area of practice is still emerging in Australia, there are a number of previous studies and reports published in Australia addressing the needs of children with parents affected by mental illness (see chapter 2). Many of these recommendations or issues are still relevant and warrant consideration and discussion by agencies that wish to assist these families and their children. A review of the literature to inform evidence-based practice in this area would also greatly assist the future development of effective support for these children.

There are a number of barriers that agencies should be aware of if they wish to effectively address the needs of these children. Some of the blocks to progress have been described in chapter 2. These include apprehension on the part of the parents themselves, lack of clarity by agencies with regard to responsibilities, roles and practices, and concerns by workers about their expertise in this area. Authors such as Campbell (1999) identify a number of barriers to effective interagency collaboration, along with practical strategies to overcome these. This type of information must be disseminated and strategies must be identified to assist the development of these skills among staff.

Consultations have also indicated that funding has been a barrier to carrying out many of the recommendations suggested, such as employment of project officers to facilitate collaboration, even though this has been demonstrated as a cost-effective strategy. For example, the Southern Partnership Project, Listen to the Children (described in Cowling 1999) was able to establish and resource four regional networks across the southern metropolitan area of Melbourne within a year by employing one full-time project officer. Another year of funding would have allowed consolidation of all four groups and facilitated the development of interagency protocols (Cowling 2000), a significant and very economical outcome.

## Current practice

Those programs that do exist appear to be utilising those approaches recommended by previous Australian reports and research, including using a range of client and service-related strategies. Programs are also attempting to meet the mental health targets and outcomes identified in the MHPP National Action Plan (1999). Many programs in Victoria which are 'older' developmentally appear to be using a greater combination of strategies than other programs. However, most programs are addressing change at multiple levels as recommended by previous reports in Australia, that is direct child and/or parent support programs, collaborative practice to better utilise existing services and organisational culture change.

Program activities appeared to be highly collaborative, meeting the needs of a broad age group, utilising a broad range of service strategies and meeting a large number of mental health outcomes as described by the MHPP National Action Plan (1999). Other best practice activities include the degree of consumer consultation in development of programs, including with young people themselves, and direct involvement of consumers in some service-delivery programs, for example staff education and cofacilitation of a parenting group for parents with a mental illness.

## Collaborative service delivery

The issues involved in collaborative service delivery for these children and their families are complex and need careful examination with a view to achieving practical solutions. As identified previously, the problems faced by these parents and their children are complex and require comprehensive solutions that are not within the capabilities of any organisation on its own. The high degree of collaboration across a wide range of agencies—in the mental health sector and other areas—within current programs is promising (see table 9).

Children or their parents may present to a wide range of agencies, many of which are not mental health services, for example child protection services, education departments and juvenile justice services. Not all workers within these agencies will be able to identify and meet their needs effectively. For example, Intellectual Disability Services in South Australia identified that they frequently work with severely developmentally delayed children who live with a parent who has a mental illness, and would find it useful to have a better understanding of these issues and the resources and

support available. The poor representation of non-mental health organisations in the returned questionnaires indicates that many do not have an awareness of the particular needs of children with a mentally ill parent and their families. Other consultations indicated that generic agencies require support and training to work with families where a parent has a mental illness, and resources and commitment to support this are difficult to obtain. It was also clearly indicated that collaborative work is time consuming, as is training staff.

In addition, it should be recognised that the children and families involved are all highly individual and have different types and degrees of need; thus mental health promotion and preventative strategies will vary from family to family, child to child. For example, for some children it may be simply sufficient to provide them with appropriate and timely information regarding their parent's illness and general support. Other children will be at high risk and need to be safeguarded through very intensive support and intervention, such as that offered by the Families Together program (Edwards & Mitchell 1999), where 19 families were supported by three workers over a four-year period.

Most collaboration appears to be between adult and child mental health services. This relates to an important issue to do with collaboration—that is, who is responsible for these children? Adult mental health services are in a key position to identify people who have a mental illness and are also parents, offer general support and information to these children and to refer them to other services if required. However, consultations indicate that the adult mental health service model may not allow identification of the child as a service recipient and may not facilitate a family-focused service incorporating liaison and consultation with a broad range of agencies. In addition, AMH workers may not be equipped to assess parenting capacity and the impact the parent's mental illness may be having on the child's own mental health.

Child and adolescent mental health services, on the other hand, are well equipped to work with children and families but cannot if clients are not referred. The children and families involved may also not need this degree of intervention. As previously mentioned, these parents and their families may present to a wide range of other agencies owing to dual diagnoses or multiple problems, for example drug and alcohol services, juvenile justice and child protection services. The situation is further complicated in most States because services are perceived as fragmented and underfunded, with gaps created by eligibility definitions narrowly determining who is responsible for the child or parent. Consultations indicated that these problems might be increasing with the advent of outsourcing, as well as the competitive approach that applies to this process (Campbell 1999).

Consultations indicated that consideration needed to be given to ensuring that:

- ❖ these children are identified by AMH services;
- ❖ appropriate intervention is offered and maintained through adequate funding, for example holistic and family-oriented responses, rather than individualistic or 'medical' responses (the children's needs will then receive appropriate attention and the adult clients will be supported in their parenting role);
- ❖ case-management responsibilities are clearly identified and allocated;
- ❖ the needs of the children are accurately identified and case-management strategies include appropriate referral and liaison;
- ❖ generic agencies are supported in providing service responses tailored to the special needs of these families; and
- ❖ change is facilitated and required at all levels of management and service delivery (federal, State, organisational and individual), and is directed to all levels of intervention (child, parent/family and organisational service/policy) with a clear collaborative focus.

Strategies such as placing workers with child and family mental health expertise within AMH services to act as a resource to the AMH team have been found to be achievable and useful in some New South Wales area health services. Finally, it must be determined who is to pay for these types of activities.

Collaboration raises two main issues: first, how can services best work together to provide a network of support for these children and their families and, second, who is responsible for these children?

Lastly, consideration must be given to confidentiality issues involved in collaborative work. Adults with mental illnesses have the right to confidentiality regarding their illnesses and their treatment. However, some information may have to be released to ensure an appropriate response to their needs as parents or their children's needs for support or intervention. Conflicting duties of care, professional and ethical obligations may make it difficult for mental health workers to determine what information it is appropriate to release, and to whom. O'Hanlon and Obradovic (1999) and Ross (1999) address some of these issues. Defining the issues around client confidentiality and agreed protocols for workers with

regard to what type of information should be shared, when and how, will be critical to ethical collaborations in which both the adult clients and the children feel safeguarded and empowered. It is critical that confidentiality issues do not preclude the possibility of such collaborative activity.

## Prioritisation of workload

Questionnaire responses indicated that many of the programs were grappling with the issues raised regarding collaboration, and that service-related initiatives, for example joint case consultations, were more likely to be employed than direct client service activities, for example peer-support groups. This is not unexpected, as discussed above, as service-related initiatives better utilise scarce resources, and direct client services are more resource intensive. This highlights the dilemma present for all agencies that are attempting to meet a high level of secondary and tertiary service responsibilities within limited budgets, while trying to engage in prevention and promotion activities that may reduce secondary and tertiary service demands only in the long term. Consultations indicated that all services are in the position of having to prioritise staff time to meet overwhelming client demands and that promotion and prevention activities are lower on the priority list than direct responses to children or adults in crisis.

## Hidden children

Other service-related issues that were raised during consultations included the concern that these children are still 'hidden', despite the increasing awareness indicated by the questionnaire responses. In some States, intake procedures by AMH services are now being modified to make sure that workers inquire about the client's family status, ensuring that clients who are also parents will be identified. This is an excellent first step in ensuring that the children's support needs, if any, are considered, as well as identifying whether the clients themselves would benefit from support in their parenting role.

However, currently, record-keeping and funding arrangements usually revolve around numbers of clients seen, regardless of the number of occasions that they have been provided with a service. Thus mental health promotion and prevention activities with these children and parents are often not 'countable' and do not attract funding. It would also assist workers if the time involved in taking a family-centred approach was acknowledged by these record-keeping and funding arrangements.

## Meeting the need

As mentioned previously in this discussion, many of the specific programs to meet the needs of children with parents affected by mental illness involved appropriate, but indirect and less resource-intensive, measures that related to service-delivery strategies.

As the awareness of the needs of these children and families is a recent development in Australia, it can be expected that many programs will focus on service-delivery strategies as a first step. These include better identification of the children; sharing ideas and resources between agencies, including enhancing interagency collaboration; advocacy for the needs of the children and their parents; and awareness raising and education for staff.

Areas that the questionnaire responses indicated were less frequently addressed (50% or less of programs responding 'yes' to this question) included:

- ❖ the mental health target (from the MHPP National Action Plan 1999) of promoting child and family participation in school and community activities (40.9%, see table 4); and
- ❖ direct client-service strategies used (see table 5):
  - { support groups for children whose parents have a mental illness (50.0%),
  - { support groups for parents who have a mental illness (39.3%),
  - { camps for children and their parents (39.3%),
  - { home-based support (35.7%),
  - { supported accommodation for families where a parent has a mental illness (10.7%), and
  - { respite care for families where a parent has a mental illness (17.8%).

It is quite clear that many of these strategies are particularly resource intensive, as opposed to the service-delivery strategies that frequently enable scarce resources to be utilised more effectively. Consultations also suggested that

some funding agreements made with agencies may not support long-term, flexible support strategies for these children and their families.

Although economic realities must be acknowledged, the poor availability of home-based support, respite care and supported accommodation is a major concern. These are the services that parents who have a mental illness are themselves indicating in particular to support them in their parenting role (Farrell et al. 1999; Hearle et al. 1999; Kalucy & Thomas 1999; and Cuff & Mildred 1998). For example, the report by Hearle et al. (1999) indicated that support needs identified by parents with serious mental illness included:

- ❖ specific support groups for parents, dependent and adult children and partners;
- ❖ in-home and out-of-home respite care;
- ❖ home help; and
- ❖ practical support and assistance in caring for children.

Of the 44 programs identified nationwide, currently 14 programs offer support groups for children, 11 for parents, ten offer home-based support, five offer respite care and three offer supported accommodation tailored to the needs of these families.

It was pleasing to note that one program in New South Wales has plans to address the needs of children of parents who have mental health problems arising from their experiences as refugees or migrants. Consultations across a number of States and some policy documents, for example the Mental Health Promotion Plan 1999–2002 (VicHealth 1999), indicated that services are aware that programs must also be developed to specifically address the needs of Indigenous children and children living in rural (as opposed to regional) centres or remote areas.

## Evidence-based practice

Finally, the MHPP National Action Plan indicates that the evidence base related to children with parents affected by mental illness requires development, with further research and evaluation. This is confirmed by the low level of research evidence cited by programs (see table 13), with 29 programs indicating no research evidence and the remaining 15 programs not indicating more than two levels of evidence.

Responses also indicated that there may not be a clear understanding by workers of what comprises research evidence, for example Cowling (1999) was sometimes cited as an example of evidence-based research in the field. While this work is a very important summary of descriptive research regarding the current situation, existing practice and issues, it does not provide (and does not profess to) information on research-based trials of intervention strategies.

A number of comments in the questionnaires and during consultations indicated that, while acknowledging the importance of basing interventions on proven strategies, organisations did not have the resources to allocate staff time to identifying, critically examining and circulating the evidence base regarding these children. It seems likely, therefore, that the activities of most programs are selected and directed on the basis of workers' professional judgement and experience.

This is further complicated by the fact that the knowledge base, as derived from rigorous research, is scarce with regard to the impact of mental illness on children and their families, risk and resiliency factors and effective interventions. Interest was expressed by workers regarding the evidence base for the prevalence of mental illness/mental health problems among children in the long term, the effectiveness of respite care, and appropriate targets for intervention.

While workers are hampered by the scarcity of research evidence for their practice and difficulty in accessing this information, their commitment to program evaluation is high, with 31 of the 44 programs including an evaluation component (see table 14). This is perhaps in accordance with the pragmatic approach espoused by Ustun and Jenkins (1999) and quoted in the document *Prevention Initiatives for Child and Adolescent Mental Health: NSW Resource (1999)*:

It is important that we look towards investing in effectiveness. The true test of a prevention program is not the efficacy and effectiveness in the research setting but the effectiveness in the real-life setting with the community in charge of the program.

It is important to remain realistic in terms of research. Research results will be noted in the long run as we fine-tune our programs, but in the early stage of knowledge we have to make a start somewhere, otherwise we would not have anything to evaluate and we would never gather significant evidence.

This commitment to examining the effectiveness of their practice is to be encouraged; however, at this point the evaluation components included would not contribute to recognised research by gathering 'significant evidence'. This high level of commitment to evaluation and expressed interest in basing interventions on sound evidence could be capitalised on by providing the types of support that would help to produce further research-based evidence. Thus it may be that, if expert assistance is available to integrate appropriate research methodology into the program evaluations used by current intervention programs, the research evidence required will be generated.

As meeting the needs of these children and their parents is a national strategy, it is important to know where these children are, what their needs are and whether programs being implemented are of assistance. Consideration should therefore be given to national collection and monitoring of such data, as well as analysing the research evidence as it currently exists and disseminating the results to practitioners in the field.

## SUMMARY

The project was successful in gathering a great deal of relevant information and identifying issues that require attention. The findings clearly illustrate that there is an emerging awareness across Australia regarding the existence of this group of children and the developmental risks they may be experiencing, and a move towards identifying and meeting these needs. Policy frameworks to support mental health services in recognising the needs of both the parents and their children, and responding effectively, are either in place or under development in most States.

As would be expected, some States, for example Victoria and New South Wales, are further developed in their responses to these children and families than others, but initial collaborative or research work to identify and address the needs could be identified in all States. Those programs that are available target those strategies and responses currently understood as most helpful for these children and their parents. This included addressing the needs of the child, the needs of the parent and initiating change at a policy or service level.

Considering the issues identified by the study will help the States and Territories continue to move forward in addressing the needs of these children and families. A flexible network of support should be available in our community which clearly requires a high degree of interagency collaboration. These children and their families are highly individual and have different types and degrees of need at different times, so the type of support required will vary and must be flexible and responsive. These children, and indeed their parents, may present to a wide range of non-mental health agencies, who should be aware of this, know how to respond appropriately and know the resources that are available.

There are a number of challenges to such interagency collaboration that require consideration. Agencies are not always aware that the adult who has a mental illness is also a parent and they are often concerned about the AMH client's right to confidentiality. The parents themselves may fear that they will lose their children if they indicate they need help. Agencies should also be clearer about their responsibilities, roles and practices.

A number of States have already begun addressing the initial identification of the existence of these 'hidden' children by asking AMH clients on intake whether they are parents. Other positive changes that are underway in some services include developing strategies in AMH services that are holistic and family oriented, and reorienting services to prevention of mental health problems and the promotion of mental health. This will be assisted if AMH workers are educated about identifying the needs of children, and of parents with regard to their parenting role, and initiating appropriate referral and liaison with other agencies. Many workers indicated that the amount of time this takes, as well as current record keeping and funding arrangements, are a barrier to working in this manner.

Some programs were able to provide services that have been identified by parents who have a mental illness as a high priority. These include services such as support and skill development groups for the child, similar groups for the parent, in-home support (for example, immediately after hospitalisation), planned and emergency respite care with consistent caregivers, and supported accommodation. While these types of services are resource intensive, both

consumers of AMH services and workers from a range of agencies clearly indicated that such services were greatly needed.

One program has begun to identify the needs of children of migrants experiencing significant mental health problems. However, the needs of Indigenous communities, children living in rural and remote areas (as opposed to regional country centres) are yet to be specifically addressed.

Finally, responses indicated that workers acknowledged the importance of using research evidence as a foundation for their practice, and were interested in accessing this type of information. However, workers were hampered by time and resource constraints in identifying and analysing the research, and by the fact that the evidence regarding effective interventions for these children and their parents is scarce. In addition, respondents to the questionnaire did not always have a clear idea about what was meant by the NHMRC's evidence-based standards. Nevertheless, a high level of commitment to program evaluation indicated that, with expert assistance, there may be opportunities for program providers to participate in further developing the research evidence base by upgrading their program evaluations to contribute to this type of research information.

The data-gathering and consultation processes indicated that a number of recurring themes were important and these included the following:

- ❖ It is not clear whose clients these children are.
- ❖ It is not clear how a multisystemic approach and a network of support can be provided.
- ❖ It is not clear how needs can be met effectively, that is to provide intervention and support that is flexible and not time limited.
- ❖ Very few programs exist nationwide that are specifically designed to meet the needs of children with parents affected by mental illness.
- ❖ The States are at different developmental levels with regard to their awareness of the needs of children with parents affected by mental illness and program responses to these children. No States are adequately meeting the needs.
- ❖ The needs of children in cultural circumstances differing from the mainstream of Australian society—for example, those in Indigenous, migrant and rural or remote families—are not being met.
- ❖ Less than half of those programs that do exist are addressing the support needs identified as highly important by parents who have a mental illness.
- ❖ Programs must be reoriented from cure to prevention, so that they encompass a full range of interventions and strategies to effectively promote the mental health of children with parents affected by mental illness.
- ❖ It isn't clear what obstacles must be dealt with in moving from an adult, individual-centred service delivery to a holistic service that recognises the children of adult clients and the wider roles, for example that of being a parent, that the adult plays in their community, and their importance to all family members' mental health.
- ❖ It also isn't clear how prevention and promotion work can occur when funding is based on numbers of clients seen, not even on the number of times they receive a service. Adequate resourcing must be secured for promotion and prevention work.
- ❖ Funding is stretched to meet current demands. These children are low on the priority list, for example potential suicides are often first. Reliable funding is needed because short-term funding does not allow sustainable projects to be developed, and more funding must be directed to promotion and prevention activities.
- ❖ The evidence base underpinning the work of these programs is sparse, and this information should be identified and circulated to agencies, along with information about current best practices.

# 7 Recommendations

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Some recommendations can be made on the basis of information gathered so far by this scoping project. The following recommendations were developed with the assistance of the reference group for the project and further refined after consultation with the PPWP and the federal Department of Health and Aged Care. Recommendations are grouped under three headings: mental health services, intersectoral collaboration and research and education.

## Recommendation 1: Mental health services

Recommendation 1.1: An expert multidisciplinary group should be convened to develop and disseminate clinical practice guidelines for child and adult mental health services on appropriate responses to children with parents affected by mental illness and the parents themselves. The Commonwealth should then publish these standards and encourage their adoption by mental health services.

There is room for improvement among mental health agencies in identifying and responding to the needs of children and parents in families where a parent has a mental illness. An expert multidisciplinary reference group of key professional disciplines in mental health service delivery could be convened to develop these guidelines. An organisation that has a multidisciplinary focus across sectors, such as AICAFMHA, could be contracted to coordinate this consultation and disseminate the guidelines once they are developed.

Endorsement of these guidelines by the National Mental Health Working Group would facilitate their use as part of routine clinical practice for all mental health professionals. These clinical practice guidelines will develop the knowledge base of practitioners and incorporate good practice principles for working with this population, including:

- ❖ identifying these children, and all family members (this requirement should be considered in the context of the conclusions and recommendations in the document *Toward a national approach to information sharing in mental health crisis situations* [2000]);
- ❖ assessing, and determining the appropriate response to, and the needs of, these children, including offering or facilitating access to a broad range of support and intervention options in both the mental health and other service sectors, such as family support, peer-support programs, education and so on;
- ❖ determining parents' needs and assisting parents in accessing resources to support them in their parenting role, such as peer support, and respite and in-home support;
- ❖ clearly identifying and allocating case-management responsibilities for families with a mentally ill parent, particularly where a number of agencies are involved;
- ❖ supporting generic agencies in providing service responses tailored to the special needs of these families (possible strategies are described under recommendations on intersectoral collaboration below); and
- ❖ ensuring that the rights and confidentiality of all family members are addressed and protected.

Recommendation 1.2: An active dissemination and communication strategy should be developed for the guidelines prepared under Recommendation 1.1 to ensure their rapid uptake by mental health services.

To ensure rapid uptake of protocols and clinical guidelines, an active dissemination and communication strategy must be implemented under the auspices of the PPWP. This should be a multilevel strategy and include booklets on the guidelines, dissemination via electronic media and presentations at conferences. Appropriate networks could be contracted to develop and implement these dissemination strategies, for example AICAFMHA, the Mental Health Council, and the Annual Mental Health Services Conference of Australia and New Zealand.

Recommendation 1.3: The States and Territories should give consideration to putting in place programs that adhere to current understanding of the most effective responses to the needs of these children and their families, and meet the needs identified by the children and parents themselves.

The scoping study indicates that there are currently few programs across Australia that directly address the needs of children with parents affected by mental illness, and indirectly support the children by assisting their parents in their parenting role. A focus on developing such programs would be complementary to the implementation of the guidelines

and strategies developed under Recommendation 1.1, and meet a current need in the community.

## Recommendation 2: Intersectoral collaboration

The scoping study highlighted the fact that children with parents affected by mental illness have different needs and issues, and may never present to a mental health agency. They may instead come into contact with other agencies, where opportunities to respond appropriately to their needs—either within that agency or through referral to more specific services—may not be recognised, and the children continue to be ‘hidden’. The following recommendations address this issue.

**Recommendation 2.1:** Mental health services should take a leadership role in developing protocols, linkages and coordination across all sectors involved with children. This collaboration would aim to help other agencies identify and respond appropriately to children who would benefit from support as a result of a parent’s mental illness.

Children may present with issues related to their family circumstances to general health services, general practitioners, and welfare, family court and education sectors. Collaboration across these sectors by mental health services would be facilitated by the development of the guidelines suggested in Recommendation 1.1 and through the endorsement of the PPWP. Commitment to and implementation of this collaborative approach should be facilitated and required at all levels of management and service delivery (federal, State, organisational and individual) and be directed to all levels of intervention (child, parent and family, and organisational service and policy).

**Recommendation 2.2:** Information on the needs of children with parents affected by mental illness, their parents and families should be widely disseminated to all sectors.

Both federal and State and Territory mental health agencies are in a position to raise awareness and educate the agencies that are likely to come into contact with the children and their parents regarding identification and appropriate responses. Dissemination of information on their needs to mental health agencies, and agencies with which mental health agencies will be developing linkages, will assist in uncovering these ‘hidden’ children and families. Dissemination strategies could include presentations at conferences, State-based consultations and education activities, professional and continuing education courses, and web-based strategies. Appropriate networks could be contracted to develop and implement these dissemination strategies.

**Recommendation 2.3:** State and Territory mental health agencies should investigate strategies for educating and supporting all agencies or organisations who are likely to come into contact with parents who have a mental illness and their children about the special needs of these clients.

These activities should involve establishing collaborative strategies to assist agencies to meet these families’ needs. Strategies could include presentations at conferences and meetings of peak bodies, and targeted mail-outs of information.

**Recommendation 2.4:** Barriers to appropriate and collaborative service delivery for children with parents affected by mental illness should be clearly identified, along with practical strategies for overcoming these.

A number of barriers to collaboration between mental health services and other sectors have already been identified by this report, and more may exist (O’Donovan 1994; Cuff & Pietsch 1997a; Einfeld & McLaughlin 1998; McEnroe 1998; Cowling 1999; Farrell et al. 1999; and Kalucy & Thomas 1998). Any development of guidelines or strategies arising from Recommendation 1.1 should address these barriers. Strategies for identifying the barriers and possible solutions could include a face-to-face consultation with key sectors at a State and federal level on this issue, or further indirect consultations utilising the scoping study methodology. In addition, professional development within mental health services could focus on skills needed to achieve successful interagency collaboration and solve problems.

## Recommendation 3: Research and education

**Recommendation 3.1:** The nature of mental health practice should be examined by a multidisciplinary reference group of key mental health professionals with a view to reorienting it to support the clinical practice guidelines identified by Recommendation 1.1.

Current practice and funding models within most AMH services are characterised by an individualistic and ‘medical’ model. This approach does not help practitioners provide a holistic family-friendly approach that better supports the children, spouses, other family members and parents with mental illnesses themselves. A reorientation of the services could be considered as part of the National Mental Health Information Strategy. It should ensure that data collection identifies children of adult clients (including direct carers) of AMH services, and acknowledges service activities related to providing support to, and involving the children and their parents in, mental health promotion and prevention activities.

Recommendation 3.2: The expert group established under Recommendation 1.1 should give consideration to previous recommendations regarding support for children with parents affected by mental illness when developing protocols and guidelines.

A number of Australian reports by federal and State–funding bodies regarding support for children with parents affected by mental illness already exist and include recommendations that, given their recent nature, are likely to be relevant. These recommendations should be collated and examined to clarify why they have not been implemented.

Recommendation 3.3: A central, easily accessible and updated resource should be developed that provides access to, and analyses, current research evidence regarding the needs of children with parents affected by mental illness and their families, and also promotes the guidelines developed under Recommendation 1.1.

Time constraints incumbent on mental health workers make it difficult for them to access and analyse current research evidence related to the needs of children with parents affected by mental illness and their families. If they do have time to carry out this work, it may represent a duplication of effort as few reviews appear to be published. An organisation such as the federal Department of Health and Aged Care could contract AICAFMHA to develop such a resource, and make it available nationally.

Recommendation 3.4: States and Territories should investigate strategies to provide expert research assistance to service delivery staff to enable them to develop program evaluations based on research principles, and to support them in documenting, analysing, publishing and otherwise disseminating this information.

Most of the programs to support children with parents affected by mental illness indicated that they were engaged in evaluation activities but that these activities are not research based and will not contribute to the evidence base for this area of practice. States and Territories could consider strategies such as collaboration with universities or government health research units to maximise opportunities to further develop the sparse research evidence available on successful interventions for these children and their families.

Recommendation 3.5: Knowledge regarding ‘good practice’ programs and activities for children with parents affected by mental illness should be promoted and shared widely.

Experience in Victoria has indicated that the strategy of promoting and sharing knowledge of ‘good practice’ programs has assisted in further development of programs and strategies for children with parents affected by mental illness in that State and around Australia. First, the information regarding programs and practices gathered by this scoping study should be disseminated. It is recommended that this type of information be shared across Australia through as many avenues as possible, for example in conference presentations and by placing information on the AICAFMHA website. A mechanism for continued peer review and updating of these programs on the AICAFMHA website would greatly facilitate networking and development of support.

## 8 References

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