



## Consulting with young people about service guidelines relating to parental mental illness

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### Abstract

Information from children of parents with a mental illness was specifically sought in the development of a key document for the Australian Government regarding good practice principles and guidelines for services and people working with these young people and their families. This paper describes one of the consultation phases where young people in the 7 to 20 year age range were asked to comment, via focus groups and peer interviews, on issues raised in an early version of the document. The participants gave suggestions regarding 'family friendly' mental health facilities and services and supports that would benefit families and children affected by parental mental illness. The young people reported that additional care-giving responsibilities, communication problems (with service providers and between families), lack of appropriate practical and emotional support (for the person with the illness and for the family), the need for universal education and stigma reduction regarding mental illness were key issues affecting families where a parent has a mental illness. Similar to other studies in this area, the consultation found that supportive adults, siblings or peers, participation in activities, relevant information, 'time out', and someone to talk to were factors that helped young people to cope with their parent being unwell.

### Keywords

youth, children, family, mental health, consultation, policy

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### Background

Children of parents with a mental illness have been described as a largely 'invisible' population at increased risk of developing mental and physical health problems and of leaving school earlier than their peers (AICAFMHA, 2003; AICAFMHA, 2004; Carers Australia, 2001; Cowling, 1999; Falkov, 1998; Falkov & Lindsey, 2002). A limited number of small scale qualitative studies in Australia (Handley, Farrell, Josephs et al., 2001; Maybery, 2002) and overseas (Aldridge & Becker, 2003; Armstrong,

2003; Garley, Gallop, Johnston & Piptone, 1997; Webster, 1992) have sought information from the young people themselves about their experiences, needs and coping mechanisms. Themes from these studies include the struggle by young people to understand the illness and to manage the impact of the illness (especially at key times of crisis such as hospitalisation of the parent), and the taking on of age-inappropriate responsibilities (emotional and practical). Some young people also raised issues relating to the poverty and limited social networks often associated with adult mental illness. All studies

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indicated that relationships with family members and friends, ‘someone to talk to’ and involvement in activities, assisted the young people to cope with their situation, although a small number of apparently inappropriate coping mechanisms were also revealed (e.g. withdrawal).

In 2002, the COPMI (Children of Parents With a Mental Illness) initiative of the Australian Government invited people with mental illness, their carers, children and service providers to participate in discussion groups to identify what should be included in practice guidelines for services and people working with children of parents with a mental illness. Information from the consultation was combined with evidence from the literature and from experts from the field. A discussion paper (AICAFMHA, 2002) was developed, promoted and circulated for public comment. Feedback was subsequently considered in the development of *Draft Principles and Actions For Services and People Working With Children of A Mental Illness* (AICAFMHA, 2003), and a final document (AICAFMHA, 2004) was produced after further extensive consultation. The current paper relates specifically to consultations with young people after the discussion paper had been released in 2002.

## Method

### *Procedure*

A plan for gaining feedback from children and young people on key areas of the discussion paper was reviewed by the COPMI Reference Group (a nationally representative sample of experts, consumers and carers with knowledge in the area), and 15 workers known to run support programs for children of parents with a mental illness (‘copmi’) in various locations in Australia. The two methods proposed for data collection were focus groups for children in the 7 to 12 year age range and peer interviews for young people in the 13 to 20 year age range. Draft questions for the focus group facilitators and peer interviewers were included in the plan.

Feedback from reviewers led to the development of a final list of 12 questions for the children and 14 questions for young people, of which 8 and 10 questions respectively were directly related to

issues raised in the discussion paper. The other four questions were designed either to gain information to assist in the development of related health promotion materials for children and young people or to assist the interview or group process, and they are not addressed in this paper.

Invitations were sent to 13 leaders of ‘copmi’ support programs across Australia to assist with the consultation methodology and in gaining participants. The roles and responsibilities of focus group facilitators and peer interviewers (youth consultants) were clearly stated in the invitation. Seven leaders offered to assist: three were happy to conduct focus groups with 7 to 12 year olds, three offered to support youth consultants to undertake the peer interviewer role and one ‘copmi’ program leader offered to facilitate focus groups for both age groups.

The use of a third person to collect the information (focus group facilitator or youth consultant) ensured that participants were speaking with someone with whom they had a trust relationship.

### *Participants*

#### *Children aged 7 to 12 years (focus groups)*

Thirty three children participated in a total of six focus groups held in the suburbs of State capital cities (Adelaide, Melbourne and Hobart) and in rural New South Wales. Fourteen participants were male, 13 were female and the gender of the remaining 6 participants was not recorded.

#### *Young people aged 13 to 20 years (focus groups and peer interviews)*

Twenty five young people participated, 16 across two focus groups and 9 in peer interviews. The participants lived in the suburbs of three State capital cities (Perth, Sydney, and Adelaide) and in rural New South Wales. Focus group participants were aged between 13 and 16 years and peer interview participants were aged between 14 and 20 years. Eight participants were male, 15 were female and the gender of the remaining two participants was not recorded.

### *Protections afforded to participants*

The program leaders and youth consultants gained the informed consent of the young people (or their parents/guardians in the case of those under 18 years) to participate in the study. All

data were de-identified before being provided to the COPMI Project Manager. In recognition that the youth consultants and participants may experience adverse effects as a result of the interview process, program leaders were asked to offer follow-up support. Youth consultants and interview participants were offered support both verbally prior to the interviews and in writing as part of the consent process.

### ***Analysis***

The responses from the children and the young people were collated and reviewed by two COPMI Project Team members who separately noted key themes arising from the responses. The collated data and key themes were then discussed with the COPMI Reference Group. Not all of the 33 children aged 7 to 12 years were asked every question; numbers are indicated below where this is the case.

## **Results**

### ***Responses from 7 to 12 year olds***

#### ***Hospital facilities and environment***

The children were asked to comment about how and if hospitals for adults with mental illness could be improved for child and family visitors. Their responses fell into five key themes of privacy, opportunities for family focused activity, ambience, access and information.

Many children asked for private areas where their family could meet, talk and relax together and they gave suggestions about facilities that could enhance activities the families could engage in together (e.g. 'home-like' family rooms, a playground or other play area for children, games, children's books, TV and video). Some children commented that use of private family areas would also prevent children being frightened by the behaviour of other patients.

The participants suggested that the hospital environment for mental health patients could be more welcoming (e.g. 'the wards need to look nicer', 'take them flowers like you would at a normal hospital', 'have toys and books for children', 'treat people with mental illness the same as others') and that staff could be friendlier. One focus group of children also thought that hospitals could be improved if they

provided children with opportunities to learn more about mental illness from staff.

Some children commented about poor access to their hospitalised parent, and suggested that a telephone number be given to children to enable them to call their parent, that transport be provided for children to visit the hospital, and that there be increased flexibility regarding visiting hours.

#### ***Planning***

The children were asked if they had a personal care plan that could be utilised if their parent required hospitalisation or was unwell for a long time. They were also asked if they believed a plan would be useful for families like theirs and were invited to suggest areas the plan should address.

The majority of children thought a plan was a good idea but some were happy with the informal plan currently in place within their family (e.g. 'I go to a friend's place, who is really nice', 'I stay with neighbours when Dad's working'). Content ideas suggested for the plan included telephone numbers of adults who could assist; where the children would stay overnight, after school and on weekends, or who would stay with them in their own home; arrangements for getting to and from school; who would assist with household activities such as cooking; and who would care for their pets if they had to temporarily move house. One child suggested that first aid could be included on the plan (e.g. what to do if parent overdosed or fainted). Another suggested that children ensure they know what hospital their parent would be admitted to and when they could visit.

#### ***Extra help for families***

One question centred on the type of help families like theirs may require when their parent was unwell. The children provided answers across a broad range of areas of assistance including financial ('we need more money', 'help to pay the rent'), transport (to and from school and activities), domestic (e.g. cooking, cleaning, shopping, caring for younger siblings), and social and emotional support ('more holidays and fun times', 'more time to talk about what's happening', 'time out'). One child also suggested that parents receive help with relaxation to 'calm (the parent) down'.

### *Family meetings with mental health professionals*

Twenty three children were asked about the value or otherwise of doctors and/or hospital staff meeting with the whole family when the parent is unwell, to provide information and answer questions. The majority of children supported this idea but some concerns were raised about the privacy of the information disclosed and the use of terms by medical and nursing staff that the children may not understand. One focus group provided a list of the type of things the children would like to ask, including how long the parent would be in hospital, what sort of treatment their parent was receiving, and when the child could visit.

### *Ways children cope*

The children were asked about special things in their lives that help them cope with their parent being unwell. Answers fell into four main themes: supportive adults, activity, 'time out', and someone to talk to. Some of these themes overlapped. The supportive adults included relatives, neighbours and friends. They were also sometimes mentioned as being good people to talk to. Participants also valued talking to a counsellor, pets ('they listen to you and don't yell'), peers and siblings. Helpful activities named by the children included sport, exercise, 'getting into mischief', reading, playing on the computer, listening to music, standing under the shower (thinking), cooking and watching TV. Some of these activities may also provide 'time out', but some children specifically stated that they find it helpful to get away physically from a particular situation or person.

### *How to make things better*

Twenty five children participated in groups that were asked the question, 'Are there any things you would like to see happen to make things better for families like yours; and if so, what are they?' Their responses included:

- improved care of their parent (e.g. 'better medicine', more community teams, support groups and counselling for parents);
- financial support (e.g. free transport, support to parents to pay bills and buy medication);
- emotional support for and from family members (e.g. someone to talk to, to comfort people when upset, 'more support and understanding from our families');

- information provided to all family members and to people in the community ('To stop them teasing you – that they know there's nothing wrong – anyone could get it if they get stressed out – they could get it');
- fun things for parents and kids to do together or separately;
- peer support ('we've got other kids phone numbers'); and
- seeing the person with the illness more.

### *Where to gain information about mental illness*

Children were asked, 'Where do you think children in families like yours should be able to learn about and have their questions answered about mental illness?' Many said they should be given information by their parents (not necessarily the parent with the illness) and caregivers. Others suggested other relatives, friends of their parent, counsellors ('they don't use complicated words if they're kids' counsellors'), and other health or social workers (e.g. people at the mental health centre, 'nuns or sisters', and 'nice doctors who know about kids'). Although many participants suggested that children could learn about mental illness at school, this was generally in reference to universal education only and some children expressed concerns about the confidentiality of family information in the school setting. Other suggestions included learning about mental illness by attending camps and support groups, and from the Internet, books, popular family and youth oriented magazines, a comic book and videos.

### *School support*

Twenty five children were asked to identify ways in which their school could support them or help them cope better with having a parent who is sometimes ill. They identified various people it would help to talk to (counsellors, teachers, good friends) and a range of supports (e.g. transport, 'lunch if you haven't any', breakfast programs, a place to talk to an adult after or before school). Some also commented on the need for teachers to be more flexible and caring if they know a child's parent is ill ('Teachers should ask how we are'), but they also recognised that school could be a place where they can temporarily forget about their family life. Children in one focus group commented that schools could help children

learn how to cope better and others said that they could provide information to other students about mental illness.

### ***Responses from 13 to 20 year olds***

#### *What are the biggest issues?*

The young people were asked to identify the biggest issues that affect families where a parent has a mental illness. They believed that the following issues needed to be addressed:

*Additional care-giving responsibilities* (e.g. time, financial, emotional) of parents, especially single parents, and other family members including children. In some cases it was perceived that the impact of this responsibility was increased due to the conflict it caused in the family.

*Communication problems* within families and with service providers. Some young people perceived that the mental health system did not listen to family members about the ill parent's behaviour or about the impact of medication changes etc. Young people also reported concerns that mental health workers did not communicate basic information to family members about the parent's illness and/or treatment.

*Lack of support services and facilities*, including counselling for all family members, support programs for parents and young people, financial support, access to hospital beds, and practical domestic support. In contrast, one participant was concerned that some agencies (e.g. child protection) intervene too much.

*Need for universal education and stigma reduction*, including reduction of teasing and bullying of offspring and increased public understanding and awareness of mental illness and associated support services. Some participants identified the need for increased consideration and compassion from the family court, other courts and the police, which they believed could be addressed by increased education of service providers.

*Lack of flexibility by schools* and lack of understanding of students who are also providing care for a parent with a mental illness.

*Harm prevention* was identified by one participant who suggested that medication be

provided in packs, available on a weekly basis from their local pharmacist, to reduce parental access to large amounts of medication.

#### *Identification of offspring by mental health services*

When asked about the benefits or otherwise of mental health services knowing that a person with a mental illness has children, the following benefits were identified.

- Some young people believed that knowledge of the family situation would assist staff to relate to their parent with increased understanding and patience and therefore improve patient care.
- Young people could benefit from workers' knowledge both of mental illness and of services available for offspring such as peer support programs.
- The children's needs, including those relating to their safety, could be considered both whilst the parent is in the hospital and when they return to the family.

Most young people could identify no negative issues relating to the mental health service knowing of the existence of children. However, some perceived a potential problem arising as children could be removed from their parent's care if the parent was wrongly assumed to be unfit to care for them. One participant thought that identification was unnecessary 'because older children can look after themselves'.

#### *Hospital environment*

The young people generally thought that the hospital environment for people with a mental illness could be improved by offering facilities for families. These included a family centre where families could meet together (attractive, with appropriate toys, furniture and tea/coffee facilities); a gym; a peaceful place, such as a park; separate, private visiting areas; a less restrictive environment (parent not confined to a hospital bed); and a more welcoming environment ('Do something about the smell'). They also identified ways in which staff could be more 'family friendly', such as providing information, being more hospitable and taking time to talk to young visitors.

#### *Planning*

When asked if they thought it was a good idea to have a plan in place should their parent become

unwell or be admitted to hospital, most thought it was a good idea, but mainly applicable for younger children. Some of the participants made suggestions about what could be included in the plan, such as important contact details and telephone numbers, where the child could stay if they needed to be cared for outside of the home, a plan for visiting the hospital and 'ways to run the family so it is as normal as possible'.

#### *Extra help required*

Participants were asked about the type of support services that should be accessible (if required) for families affected by parental mental illness. The following themes were noted:

- Domestic support (e.g. cleaning, baby sitting, cooking, shopping);
- Transport assistance (e.g. to and from school, visiting parents in hospital, transporting parent home from hospital);
- Respite/camps and support groups;
- Financial support (including carers' support and food parcels);
- Support for the person with the mental illness to return to work and their home life; and
- Counselling available for all family members.

#### *Family meetings*

Participants were asked about the value of family meetings with doctors and/or other mental health workers when the parent is unwell, in order to learn what is going to happen next and to have questions answered. Responses were mixed. Some young people thought such meetings could be valuable, especially in gaining information, reducing confusion and improving communication generally. One young person thought that separate meetings with individual family members were a better concept ('This way the family members can say exactly what they need to without upsetting anyone else in the family'). One young person thought family meetings should be offered as an option only.

Those not in favour of family meetings raised concerns that it could cause embarrassment for the ill parent, or be intimidating or upsetting for participants. Two young people felt they knew enough already or as much as they wanted to know. Another participant was concerned that family meetings may appear to resolve issues in

the short term but that once health workers weren't involved 'the truth would come out and the situation would be made worse'.

#### *Things that help you cope*

The young people identified many things that helped them cope with their parent being unwell, including:

- Peer support programs and carer camps ('realising I'm not the only one', people to talk to, information about mental health, 'helping me work through my emotions');
- Hobbies ('to distract me from my problems'), artwork ('to express the pain and hurt that comes from my experience'), enjoyable pastimes, music, reading; and
- Close friends, family and other support people - especially being able to talk through issues or receive support at times of crisis such as when the parent is hospitalised.

Individual participants identified what may be seen as unhealthy coping mechanisms, such as using drugs or anything that gives 'an adrenaline rush'.

#### *Things that would make life better*

When asked what would improve life for families such as theirs, the young people identified:

- More domestic support ('help around the house');
- Increased financial support;
- Improved medical support for their parent;
- Health service providers listening to family members;
- Medication available in weekly 'snap packs' (for harm minimisation);
- More hospital beds available for people with a mental illness;
- Opportunities for respite or holidays;
- Better services in small towns; and
- Education and support for family members.

#### *Where should young people learn about mental illness?*

The young people identified a range of people (parents, mental health professionals, GPs and camp leaders), carer services (e.g. ARAFEMI) and locations (libraries, help lines, community health centres) that could provide information about mental illness. They also perceived the

media to be an appropriate source of information (newspapers, magazines, television, the internet, advertisements, posters) in addition to universal education in schools.

#### *School support*

When asked if schools could help young people cope with having a parent who has a mental illness one participant said ‘no’ but others made the following suggestions:

- Teachers need to be more aware and better informed;
- Schools generally could be more compassionate and tolerant;
- Information could be provided (e.g. pamphlets);
- Work deadlines could be more flexible;
- Fees could be waived; and
- Access could be provided to school study programs if the student has difficulty studying at home.

The young people gave mixed responses about the involvement of a school counsellor; three reported on their value regarding support and information (e.g. ‘I was lucky enough to have a great school counsellor at my high school’) but two found them unhelpful (‘counsellors are usually really useless with issues like mental illness’, ‘help from the school counsellor just makes things worse’).

#### *Strengths*

As a conclusion to the focus group and interview questions, most participants were asked to identify one of the best things about living in a family such as theirs. Although two children reported that there was nothing positive about living in their families, the diversity of other responses is a salutary reminder of the many strengths of and benefits for individuals and families affected by parental mental illness.

#### *Examples from the younger children:*

- ‘She always says she loves me.’
- ‘Your parents aren’t divorced – you’re all together.’
- ‘Having someone to talk to.’
- ‘(We) have fun doing stuff.’
- ‘Seeing Mum smile when she’s happy.’

#### *Examples from the young people:*

- ‘My parents (are the best thing about living in my family).’

- ‘You know you have people who care for you.’
- ‘Individuality; we’re very different. It’s interesting hearing each other’s points of view.’
- ‘I grew up faster and am more mature.’
- ‘It’s never boring.’
- ‘It is rewarding looking after my Mum. If we weren’t caring for her I don’t think she would have come as far as she has.’
- ‘Having my brothers and sisters because if anyone understood what it was like it was them. They were my best support.’
- ‘The best thing about living in my family is the fact, even though at times it can be hard, there is always unconditional love. Having that makes me believe I can conquer anything.’

### **Discussion**

The views of a group of children and young people often described as ‘invisible’ were sought via service providers known to run programs for these target groups. Focus groups and peer interviews provided valuable information to assist in the development of a guide for service providers in this area.

The methods used in the consultation process had a number of limitations. The use of ‘copmi’ program leaders to facilitate focus groups may have negatively affected the participants’ responses (e.g. participants may not have wished to imply any criticism of their group leader or their leader’s employing body in their responses and observations).

Data collection methods were not always consistent between the focus groups as some facilitators used a scribe who took verbatim notes and others provided a record of responses developed in point form during the session. Potentially important information may have been missed in this latter form of recording. The number of participants in the focus groups ranged from 2 to 9; this could have had an impact both on the children and young people’s ability to participate fully and on ensuring each response was recorded.

Despite these limitations, the data has a richness that complements other small scale studies undertaken with this target group. Some possible solutions were provided for the problems commonly identified by young people – understanding the illness, coping in times of

increased stress, additional care-giving responsibilities, and poverty. Participants provided practical information about how they could better access information about mental illness and their parent's care, and how they could be assisted to prepare for and manage times of possible crisis (e.g. parental hospitalisation). They were able to identify areas where they, their parents or other family members could be supported practically, socially and emotionally.

As noted in previous studies, relationships with family and friends, 'some-one to talk to', and involvement in activities and/or respite were valued as part of the young people's coping mechanisms. Some unhealthy coping mechanisms were also identified.

The information collected in this consultation goes beyond identifying needs and experiences to ask questions about possible ways to resolve issues. It therefore contributes to service providers' and policy makers' understanding of some of the key issues for young people affected by parental mental illness and how they can respond effectively to these issues.

As a consequence of the information received, in conjunction with that gained from literature reviews and consultations with consumers, other carers and service providers, the following key points were included in the final document (AICAFMHA, 2004):

- The importance of 'family friendly' facilities and staff providing inpatient mental health services in supporting the continuity of family relationships and increasing access to information to family members.
- The benefits of mental health service providers assisting in the promotion of well-being and reduction of risk factors for children where parents have a mental illness by identifying any parental roles and responsibilities of people with a mental illness at initial contact.
- The value of suggesting that families develop a plan for and with children whose parent may become mentally unwell and/or require hospitalisation (especially for young children) to reduce anxiety and improve safety and care arrangements for the child.

- The relevance of access to a broad range of supports for families (domestic, transport, financial, social, etc.) to reduce potential negative impacts of parental mental illness on the family.
- The value of access to support groups, supportive adults, someone to talk to, activities and respite services in assisting children and young people to cope with any negative impacts of their parent's mental illness.
- The role of schools in providing universal education about mental health and support for individual students affected by parental mental illness (especially for young people providing high levels of parental care).
- The value of providing a range of opportunities for children of parents with a mental illness to access information about mental illness, including supporting parents and other key caregivers to answer children's questions.

The divergent views sometimes expressed within the participant groups in this study (for example on the merits of family meetings), highlight that all guidelines should be considered on an individual basis rather than as a single response to all children. They reinforce the concept of including children and young people in discussions and decisions that affect them:

*Children should be encouraged to identify the nature of their own childhood and caring requirements more, since they often subjugate their own needs in favour of the needs of their parents. (Aldridge & Becker, 2003:92)*

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