CHAPTER 12

Children of Parents with Mental Illness

ALAN COOKLIN

As highlighted in this book and in the previous edition, the family therapy field has often failed to do justice to the needs of children. This failure is most poignant for the children of parents with mental illness (Reder, McClure, & Jolly, 2000). This is probably because:

1. Attempts to include children who may have experienced severe emotional or physical traumas in a range of family interviewing approaches may make such children feel even more trapped by conflicting loyalties, fears for the parents' safety, fears of retaliation, and sometimes by having engaged in a parent's paranoid beliefs.
2. Different approaches to interviewing families, which may themselves have been valid in eliciting and intervening in particular family processes, can nevertheless pose particular problems and dangers for this group of children. For example, the use of circular questioning that includes children may unwittingly place them in untenable positions or face them with intolerable dilemmas about how to respond in front of a parent whom they may perceive as both vulnerable and frightening. Yet approaches that stress the hierarchy of relationships within a family may both misperceive and alienate a child who has had to take on caring functions for a parent with mental illness.
3. Therapists working with the families of mentally ill members have commonly avoided attempts to actively engage the children, as they have usually been preoccupied with the interactions between the ill member and more "senior" adults, which may be seen to impinge on the patient's competence and self-image.

4. Many practitioners in the family therapy and systemic fields have been so concerned to avoid "labeling" the ill member that they may then imply that the dysfunctions associated with, for example, schizophrenia are solely part of a pattern of interaction of relationships, and then refer coyly to "so-called mental illness."

In this chapter I briefly review the evidence for the impacts of parental mental illness on children and then summarize these impacts as well as some of their needs as identified by a particular group of children and young people.

Finally, I consider a number of contexts in which children's experience of, as well as misconceptions and fears about, a parent's mental illness can be both discussed and "put in their place" in a way that can make the illness more manageable for a child.

EVIDENCE BASE

Many studies confirm the increased risk of developing both emotional and major psychiatric disorders, faced by children brought up by a parent with mental illness. For example, Meltzer, Gatward, Goodman, and Ford (2000) showed that children of parents who scored above the threshold on the General Health Questionnaire (GHQ) were three times more likely to develop a mental health disorder than those whose parents had subthreshold scores, that the proportion of children affected increased in line with the scores of the parents' GHQs, and that at follow-up 37% of children who had presented with a mental health disorder, and who also had a parent who scored high on the GHQ, were showing similar disturbances after 3 years. This compared with only 14% of children of parents with low GHQ scores. In the United States the National Comorbidity Survey (Nicholson, Nason, Calabresi, & Yandon, 1999; Nicholson, Sweeney, & Geller, 1998) showed that 68% of women with mental health disorders are parents, as compared with 57% of men. Similar figures are reported in the United Kingdom (Richman, 1976; Brown & Harris, 1978; Oates, 1997) and in Australia (McGrath et al., 1999). Aggregated data suggest that having one mentally ill parent gives a child a 70% chance of developing at least minor adjustment problems by adolescence. With two mentally ill parents, there is a 30–50% chance of becoming seriously mentally ill (Rubovits, 1996). A child with an affectively ill parent has a 40% chance of developing affective disorder by age 20, as compared with a 20–25% risk in the general population (Beardslee, Bemporad, Keller, & Klerman, 1983).

Of very serious import is the finding of Part 8 reviews in the United Kingdom whenever a child is deemed to have died as a result of child abuse (Falkov, 1996). A survey of these reviews has concluded that the critical factor in many of the deaths was not the absence of mental health service input, but rather an absence of effective intra- and interagency coordination, collaboration, and communication. Child-based agencies lacked a perspective of parental mental health, and adult mental health services generally lacked any emphasis on child protection and the nature of the children's experiences prior to their premature deaths. The training manual and handbook on working with mentally ill parents and their children, published by the U.K. Department of Health (Falcov, 1998) includes evidence that the presence of mental illness in a parent has been shown to negatively affect the cognitive and language development, attention and concentration span, educational achievement, and the social, emotional, and behavioral development of children.

These findings were confirmed by Aldridge and Stuart (1998), who reported a "befriending project" for children of parents with schizophrenia. Seventy-three percent of the children reported serious distress resulting from their parent's illness—the main complaints were a sense of being ignored, pressure to be "good," false maturity, and fear of family breakdown. Similar complaints were reported by Mackereth, Gopfert, Harrison, and Mahoney (1999); the young people interviewed reported a lack of explanation of their parent's disorder and a consequent sense of personal blame and responsibility. Weir and Douglas (1999) reported that "some children seem fine on the surface, until subsequent disclosure reveals they have been suffering neglect and abuse and living in fear for years, all the time wearing a mask," and this is backed up by Yule and Williams (1990), who conclude that parents as well as other adults commonly underestimate the consequences of "critical events" on children and the degree to which children think of, and are occupied with, what has happened. They comment that "it seems that the assumption that 'out of sight . . . [means]. . . . out of mind' continues to predominate." Furthermore, Dunn (1993) found higher levels of abuse and neglect, as well as isolation, in addition to all the complaints commonly made by children, reported retrospectively by adults who had experienced a mentally ill parent as a child. Thus, this more candid reporting of abusive experiences by adults, which as children they may have feared disclosing, suggests that there may be significant underreporting of abuse by children of parents with metnal illness, even among those relatively few who are given an opportunity to talk about their experiences.

Two of the young people interviewed as part of the Kidstime program (described below) reported extreme violence that they had never reported, and that had not been reported by neighbors or detected by the child protection services:

Helen was 17 when interviewed, and was only now living in a supported independent hostel. At the age of 10, she had been returned to the care of her mother by her father. The mother, who suffered from long-term schizophrenia, would frequently beat her if she thought she saw Helen grin and would scream that she (Helen) was a whore and was giving " 'blow jobs' all round the area." Helen had several times feared that her mother would try to kill her.

Alison was 19 when she gave birth to twins, the birth of whom made her own experience of her mentally ill mother even more poignant. She had managed the family bills and buying of food from age 11, while her younger sister had been their mother's emotional support. She described extreme violence: their mother smashing the TV if she thought there were jokes against herself and often attacking the girls if she thought they were laughing. Recently she had poured turpentine over Alison and chased her with a cigarette lighter when she had not wanted Alison to go out.

In neither case had there been any professional intervention or explanation offered to the girls until, in Helen's case, she was placed in independent living at age 17, and in Alison's case, at age 18, an enlightened psychiatrist decided to investigate what was happening in her family.

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A number of factors, particularly the presence of an alternative caring adult, can mitigate the negative effects described above (Schachnow, 1987). Rutter (Quinton, Rutter, & Gulliver, 1990; Rutter, 1987, 1990; Rutter & Quinton, 1984) identified a "capacity to appraise" stressful situations, particularly through the availability of a warm, concerned, but relatively noninvolved adult as a significant protective factor, and Cowling (1999) confirmed that the availability of one or more adults with whom a child can develop a supportive relationship is a key factor in the child's development of resilience in the face of parental mental illness. Falcov (1997, 1999) has further shown that the degree to which a child can develop a "good" explanation of a parent's mental illness—that is, an explanation that is reasonably accurate, lowers the child's confusion and self-blame, and raises the child's self-esteem—is associated with a lower level of "caseness" on the Rutter scale.

So it is clear that doing something about it for the children when a parent suffers a mental illness can have a significant protective impact. At the extreme end is adoption, as described by the Finnish adoption study (Tienari et al., 1985, 1994, 2004). These investigators demonstrated that the children of mothers who had schizophrenia, and who were subsequently adopted, had an incidence of schizophrenia that was similar to that of those who stayed with their mothers, when the sample was looked at as a whole. However, when the quality of the relationships and family environment in the adoptive families was optimal, they then found that the adopted children had an incidence of schizophrenia that was not significantly different from that in the general population. This suggests that good relationships and family environment can have a powerfully protective function.

Yet not all children with a mentally ill parent show evidence of significant harm, and some parents struggle to protect their children from the effects of their own illness.

Kate (her real name, used with permission; the boys' names are changed), now the lone parent of Sean (age 6) and Alec (age 5), said, "It's strange, mental illness . . . although you can't really control it, when you have children you really do try to minimize its effects on them." In Kate's case she had largely been able to help Sean to get over his fears (of her relapse, or that when she was angry it meant she would become ill again) by talking to him sensitively about the experience. She had found this much more difficult with Alec, however, who often voiced fears about her dying, probably because he had developed very little language by the time she was admitted to a psychiatric hospital.

Alice wanted Peter (age 13) to "understand why his mother kept going to the hospital." He would often retort that he "couldn't remember," to which she would respond that he "didn't want to remember." But Peter was able to introduce some humor, which his mother could then enjoy and join in with: "The only thing I remember is when she tried to rescue frozen chickens from Sainsbury's (supermarket)—I thought it was hilarious . . . I thought the police would arrest her, but they didn't." His mother then countered, "Well, they actually did, but they let me off."

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Both of these discussions occurred when the parent and children were present, and although I was present to encourage the discussion, I was not there as a therapist. I discuss later in this chapter how important it is for many children and young people that these discussions *not* be defined as therapy. These were therefore both "invited" discussions by the family; in the second case, this was a discussion they had not had before, and certainly had not been able to laugh about before. When such discussions between parents and children can happen either spontaneously or by "invitation," they frequently offer considerable relief to the children. But not all parents can keep their own needs, desires, and cravings separate from their children to this degree and may insist that their children support or even share, for example, their delusional beliefs. For example, Alison (mentioned above) described how she could eventually begin to see the bugs that her mother insisted were on her body.

Angelina, 16, and her sister Sabay, 14, were from Nigeria. Their mother had suffered an intermittent mental illness for the 7 or 8 years since they had arrived in the United Kingdom. She had not been violent, but they had often been frightened of what she might do to herself and had arranged that one of them would always share a bed with her. They were highly critical of the mental health services and claimed that the delays or reluctance to admit their mother to the hospital had placed an intolerable burden on them. They cited one occasion when they were aged 15 and 13, respectively, on which their mother was admitted. They claimed that social services had simply given them an amount of money—insufficient to cover the debts for electricity and other items that their mother had accrued—and left them to their own devices. But despite their struggle and distress, they had shown great resilience, had survived well, and Angelina had earned straight A's in her exams. They had accessed the Internet and spoken to their church pastor for explanations of their mother's illness. What Angelina then wanted to talk about was the effect on herself and her own life. Although she did not believe that friends had tried to reject her, she complained that she felt “apart” from other people, that she could identify neither with adults nor with children or young people. She had not wanted counseling or therapy, but described staying on her own and crying about her loneliness. She said that the first time she had allowed herself to engage socially with others had been at the Kidstime workshops (described in the following section), but that even here she had wanted to join the parents’ rather than the young people’s group. In the midst of her musings she suddenly interjected, “But you do really feel suicidal often.” For both Angelina and Sabay, although they needed eventually to find a way to talk to their mother, their first requirement was to discover that their own experiences could be described, acknowledged, and considered with, and by, someone else.

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So in this chapter I consider this dilemma and a number of possible routes to reaching a resolution that meets at least some of the children’s needs.

IMPACT OF MENTAL ILLNESS ON CHILDREN, THEIR RESPONSES, AND WHAT THEY WANT AND NEED

In the United Kingdom, a small amount of funding has been provided for those who have been defined as “young carers” of persons with metnal illness. Fortunately, this group has been quite loosely defined, so that it can really include any child whose life is significantly affected by a parent’s mental illness. The money tends to go either to local authorities or voluntary agencies, which provide evening “fun groups” where children can have time out from home worries, enjoy activities like swimming, skating, and going to the movies, and sometimes talk either individually or in a group. Most of these programs do not involve parents. The team from the Family Project at University College London Hospital—designed to introduce family thinking into (as well as to provide training for) the practice of general adult mental health providers—joined with a local Young Carers group (run by a voluntary body, the Family Service Unit) to develop the Kidstime workshops. The importance of this project was that it included both the parents (those who were or had been ill, as well as their spouses if they were still in the relationships) and the children. In fact, these were originally called the “What Shall We Tell the Children?” workshops, because our first thought was to help the parents develop an understandable explanation of their illness that they could offer their children. What eventually evolved over some 4 years was the following format. Parents and children, ranging in age from 4 to 16, would come monthly after school at about 4:30 P.M. New families would be briefly met individually, for staff members to explain the goals and format of the workshop and to establish the degree of disclosure that the parents would find tolerable. There would follow a joint seminar, lasting about 15–20 minutes, for both the parents and the children, in which some aspect of mental illness, or questions about it, would be discussed. The intensity of interest and participation in the discussions could vary dramatically from one workshop to the next, but sometimes children of all ages, together with their parents, would find a focus they could all participate in avidly. At this point, the groups would split. The parents met in one group for about an hour and discussed topics related to being a parent who has, or had, mental illness. The children started with games organized by a children's drama workshop leader and then began to construct stories, eventually producing one or more short plays (of 3–15 minutes), which we would then film. The whole group then took a break for about 20 minutes to eat pizzas, after which there would be a showing of the film of the children's play or plays for the parents and children. The discussions that followed varied from proud appraisal by the parents to intense shared discussion of the issues portrayed. The groups have become very popular, and many people attend regularly. Kate's son Sean was reported to have said to her, "Thanks for having a mental illness, Mom. I really love coming here." The group members have now participated in the production of a 1-hour training film and attached training pack *Being Seen and Heard* (Cooklin et al., 2004), distributed by the Royal College of Psychiatrists. This film reports on-screen the experiences of children and young people who have a parent who has or has had a mental illness and their experiences of professionals and of inpatient units, and, in a second part, illustrates ways of talking with children and young people, both individually and within the family. The Kidstime workshops are also highlighted as a special project.

So what have we learned from this project? First, we have learned more about the *impact of mental illness on a child*. Children and young people have complained particularly about the following effects:

- The loss of close, intimate contact with a parent.
- Neglect and/or violence, including verbal, physical, and/or sexual violence.
- Ambiguous expectations/demands; for example, one parent making demands that contradict those of the other parent, or contradictory demands from the same parent at different times.
- Invasion of the child's thinking and feelings by exposure to the parent's delusions and hallucinations.
- Fears for the parent's safety.
- Fears for the parents' future as a couple (if there are two parents), for the future of the family, and about who will look after them (the children).

- Contradictory expectations—that is, that the child be "grown up" and "a caregiver" at home, and a child at school.
- Rejection, harassment, and/or bullying by other children at school or in the neighborhood.
- Self-isolation, through stigma and fear of rejection.

A number of *other common effects on a child's life* have also been reported:

- Isolation of the family through stigma.
- Lower standard of living and financial hardship.
- Being separated from parent(s) and usual daily routine.
- Experiencing different and potentially confusing care patterns if looked after by others.
- Experiencing separation from other family members (e.g., siblings) if children cannot be cared for together.
- Disruption of education.
- Underachievement in education and reduced life chances as a consequence.

We observed the following *common responses by children*:

- Attempts to fill the caretaking space left by parents by taking care of parents and/or siblings. This can sometimes result in a child's becoming dictatorial or bullying.
- Self-blame and taking undue responsibility for the problems in the family or for the parent's illness.
- Confusion about how to interpret an ill parent's behavior, particularly the parent's anger. Confusion about whether it is the illness that causes the anger, or the anger is a result of something they (the children) have done.
- Increased compliance in response to the parent's unpredictability.
- Loyalty to the parent, through guilt and fear about the situation.
- Withdrawal and isolation.
- Depression, low self-esteem, and/or a fatalistic acceptance of their life situation.
- Attempts at dissociation from the problem, particularly if another sibling is "taking control."
- Violent and/or other self-destructive behaviour.
- Copying the parent's symptoms and/or behavior, particularly in eating disorders.

From a small study of 11- to 15-year-olds, each living with a depressed parent, Garly, Gallop, Johnstone, and Pipitone (1997) found that the children particularly wanted discussion about the following four topics:

1. Understanding the illness, including their own concerns, ideas about the cause of the illness, and access to information.
2. How to recognize the signs of an impending illness.
3. Issues to do with hospitalization.
4. Advice about management of the illness, including coping with the effect on themselves as well as on their parents, perceptions of what is helpful to an ill parent, and recommendations for other children whose parents are depressed.

The following summarizes the *needs and wishes expressed by the children* we worked with:

- To have a frank discussion about their parents' illness so they can think about the situation more objectively, and to have their questions answered honestly and openly.
- To know that there is an adult who will act as their advocate.
- To know that their situation is not uncommon.
- To have access to a place or a group where they can mix with other children and young people who have had similar experiences.
- To be helped to develop their understanding of mental health problems, and for any belief that they are responsible for the illness to be identified and challenged.
- To discuss whether they could catch the illness now or develop it later.
- To be helped to develop an understanding of how mental health services are organized and what treatment the parent is receiving.
- To be helped to recognize when a parent is becoming ill, to understand the behavioral signs that show he or she is becoming ill, and to know how to access help.
- To understand what is and what is not acceptable behavior from an adult.
- To know that their knowledge and experience of their parents' illness will be listened to and taken into account in terms of planning care.
- To know that their contribution to the care of their parents has been recognized and respected.
- To have daily life reestablished.
- To experience all the professionals concerned with both adults and children to be working together.
- To receive help and support with education, training, and employment.
- To have recognition and acknowledgment of any positive benefits of their situation.

WHO SHOULD TALK TO CHILDREN, IN WHAT CONTEXT, AND HOW?

Determining who should talk with children of parents with mental illness, and in what context and how, is bedeviled by multiple dilemmas. The first problem is that many children of parents with mental illness hide their distress because of fear, shame, loyalty to their parents, or stigma. This factor is likely to be accentuated by the degree to which a child feels responsible for the care, safety, or well-being of particularly a single parent. Second, and partly because of the first problem, most children of parents with mental illness are unlikely to manifest their distress or disturbance in common or obvious ways, such as through difficult behavior, public distress, or other symptoms. As a result, they are relatively rarely referred to child mental health or child psychiatric services, which in any case in most countries are under such pressure that they can usually respond only to children with obvious and manifest disorders. But there is another problem. In many countries the needs of a child of a parent with mental illness are little, if at all, considered by any of the relevant professional groups, which often assume that talking to children about parental mental illness is the responsibility of, or has already been done by, someone else. Mental health team workers, at least in the United Kingdom, complain bitterly about their workloads, saying that they have neither the time nor the expertise to talk to children. In fact, the mental health services in many countries are only just beginning to confront this responsibility (Gopfert, Webster, & Seeman, 2004; Ramchandani & Stein, 2003; Reder et al., 2000; Royal College of Psychiatrists, 2002). Social workers of the Children and Families Services in the United Kingdom, or the child protection services in other countries, often protest that they do not sufficiently understand mental illness and that they must give priority to major and overt child abuse cases. As mentioned, there are problems in allocating this duty to child psychiatric or child mental health services, and these services have a further disadvantage. Many children of parents with mental illness are particularly frightened of being perceived as disturbed, both because they fear following in their parents' footsteps and because the idea of being disturbed has become anathema to them. Although competent therapists can help them see that they will not necessarily follow the path of the ill parent, they often have a sense of being pulled toward the illness. This is accentuated by the fact that their own normally awkward childhood behavior may have been interpreted by one or both parents as well as by themselves as in some way a precursor of such illness (see the case of Rosa and Sergio that follows).

After 4 years of work with this group of children, our team has concluded that talking to children about parental mental illness is the responsibility of all the relevant professionals, from whichever discipline or agency is best placed at any particular time. Usually, however, the members of a mental health team are best placed to engage and help a child during, for example, the crisis of admission of a parent to the hospital. It is for this reason that the film and training pack, cited earlier, are particularly targeted toward this group of professionals. Yet, as the research on child deaths highlights, this responsibility cannot be delegated to any one group or agency, and the critical necessity is for the needs of these children to be recognized, and the response planned, across all agencies. And this does not mean demanding that a child expose all his or her feelings; it does not mean a mini-psychoanalysis of the child or even a "detective job" to find the child's worries. Some studies of the effects of various forms of trauma on children (Jones & Ramchandani, 1999) have suggested that although a "debriefing" of the experience and to gain a clear understanding of what happened to the parent and why it happened (within the limits of what is known), as well as a discussion of the future possible impact on the child him- or herself and how this can be managed, are almost universally useful, the repeated exploration of the child's experience, and the presumed "inner meanings," are often not helpful.

Whoever takes on the responsibility to help a child understand and come to terms with a parent's mental illness must consider in what context he or she will carry out this work. Moreover, although I have referred specifically to explaining *to* a child, this is a two-way process. A presentation by a group of Young Carers that I attended recently stressed that one of the worst aspects of the experience arose when mental health services suddenly realized there was a problem and became involved. The children complained bitterly that no one asked their advice, asked what they knew about the parent's illness and what made it better or worse, when they had often been managing the situation for months without help. An example is an 8-year-old girl who had been both monitoring and managing her mother's medication without any of the services being aware of it.

It is clearly best to be able to discuss the explanation of the illness, as well as the child's fears and worries, in the family, and as a family. This has the advantage that the child may experience less conflicted loyalty in describing what he or she knows and that the parents can hear about the distress the child may have been suffering. It therefore has the potential for initiating a different, more realistic, and more tolerant set of dialogues within the family. It can also be of great benefit to the ill parent, particularly if the parent can be helped to feel that simply by having such discussions, he or she is helping the child and, as a result, diminishing the guilt that most parents experience. By devising interventions that address parent–child interactions in the context of the family, the following issues can be particularly addressed:

- Attention to the children's anger with a parent who is ill.
- Helping parents assess when they can be called to account by their children for irrational or inappropriate behavior.

- Helping children know what they can continue to count on when a parent is ill (such as having their breakfast made before going to school).
- Helping parents explicitly exonerate the children of any responsibility for the illness.

Even if parents can mention their illness only in passing, this, in turn, can "give permission" to the children to bring up the subject if it is on their minds.

However, in the following example of a family discussion in which there was a reasonable degree of permission for the children to speak openly, a combination of poor professional explanation and the manner in which the family processed it, led to a dangerous anticipation that the youngest child would develop schizophrenia.

Rosa was from Guyana. She had three children—Alicia, age 13; Frank, age 11; and Pete, age 6—by her previous partner, but had now married Sergio, with whom she had a 3-year-old daughter, Maria. Rosa worked long hours as a corporate chef, and Sergio had in general taken on the child care responsibilities. He, however, had suffered several episodes of paranoid schizophrenia, during one of which he had attacked Rosa and she had then been physically protected by Alicia. Arrangements were being made for Sergio to move out of the family home, which meant that Alicia was taking on many of the housekeeping jobs, including bathing and putting to bed the two youngest children. In the course of a long discussion, for which all were present, and for which I had obtained Sergio's explicit permission for us to discuss what had happened, I asked the children what they thought caused a mental illness like Sergio's. Frank answered, " Well, I think it's if you've suffered too much stress and been too anxious . . . but I wish he'd take the medication or, if not, he should stop the marijuana." I agreed with his last point but asked, "But don't you think your mom has had a lot of stress?" Alicia and Frank agreed. I continued, "So does that mean she's going to get the illness too?" Alicia answered, "No, because it hits you in your 20s [and Rosa was a few years older]." I asked who had explained this idea. Rosa said that a psychiatrist had told them that schizophrenia runs in families and usually occurs "in your 20s." I asked Alicia if she thought this meant she would "catch" schizophrenia. She replied, "No . . . just because my dad's ill [and all the children insisted on calling him Dad, because Alicia and Frank claimed he had "done much more for us that our own real dad"], it doesn't mean I'm unhappy . . . Anyway, my Mom's there for me." Frank gave a similar answer. Alicia then said, almost in a whisper, as though trying to prevent Maria from hearing, "I've only got it on one side—my nan's [maternal grandmother]—but Maria, she's got it on both sides." So I asked, "Does that mean you think she's going to get it—schizophrenia?" Alicia and Frank both nodded and answered, "Yes." Maria was perceived by both Alicia and the other children as a difficult child: demanding, almost tyrannical, and intolerant of any control or opposition. It soon became clear that they all assumed that her behavior was a precursor to schizophrenia. Thus, a possibly well-meant explanation, combined with possible prejudices about Maria as the child of Sergio, which may have already been present in the family, had led to quite normal 2- and 3-year-old behavior being interpreted as potential illness. In turn, the reactions of other family members to Maria had then led to an accentuation of her behavior. In this case I was able to develop a form of seminar with the family as a whole in which these ideas of inevitability were successfully challenged.

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However, talking to the child within the family also carries its hazards. For many professionals it may be more difficult, particularly if they have not had the experience of talking with families. If there is not a second parent to mitigate the effects of the other parent's illness, or if the ill parent is acutely psychotic, it may be too frightening, or even too dangerous, for a child to talk openly about his or her experiences of the parent's illness—and this may be the case despite the fact that the child may have survived perfectly well with the ill parent for many months, by avoiding any disclosure of his or her own experience.

Elisa has four children: 9-year-old twin girls by her most recent, but separated partner, and boys of 11 and 14. Overtly, she encouraged them to talk, and I think she genuinely wanted them to be helped to overcome what had been some very damaging experiences. But when her younger son participated in developing a story that she thought was close to her own, she went into a rage, telling the children they would never see her again. In this instance she did at least alert the twin's father, who took them to his house, where they remained more safely for some months, seeing her on weekends. Much later, however, she encouraged the twins to talk to me on their own, but afterward was heard by the receptionist to whisper, "You didn't tell him anything . . . did you!?"

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Interestingly, this was the only case of such pressure we encountered in all the children who attended the Kidstime workshops. But it does mean that the professional needs to weigh the pros and cons to determine the best context in which to talk to a child (Gorell Barnes, 1996, 1998). However, whenever possible, it is best to ask the parent's permission to talk with the child together with them. In our experience, this is best done by explaining that this is a routine for all parents with mental illness, and that research has shown that it diminishes any negative effects of the illness on the child. We have found the following statement to be useful as an introduction that can be offered to parents:

> "Some parents may understandably want to protect their children from knowing about their illness. Unfortunately, not telling children does not necessarily spare them anxiety. Many children are extraordi-

> narily sensitive to what happens in their family, as well as to the feelings and attitudes of the adults in the family, even when these are not openly expressed. Children are nearly always aware that there is something wrong even if it is being hidden from them. As a result, if a child has a fear or worry about a parent that he or she cannot find words to express, or believes that he or she is not allowed to ask about, then in the child's mind that fear can easily be built up into something that is much more frightening than the reality. It may not occur to some parents that if a child feels he or she is not being told the truth about one particular thing, then that child may subsequently begin to distrust many other statements made by their parents and by other adults. Further, children often tend to explain all sorts of worrying events in terms of something they personally did. So if a child cannot understand what is happening to his or her parent, that child is often likely to conclude that it is his or her (the child's) fault. For a particular child, this may ultimately lead to the world's being seen as a very frightening place."

If, however, the parent is not present or does not know that the child is having a discussion with you, then it is important to explain why it was not possible to ask his or her permission (for example, because the parent was too ill to give permission at the moment). In any case, you should confirm with the child or young person that you will want to see him or her with the parent as soon as possible in order to review what you have discussed, and then you must do so.

An alternative context is to create a dedicated project that both parents and children can find both nurturing and fun such as the Kidstime workshops. The great advantage of a multifamily context like this is that it allows the children to feel less alone with their fears and worries, it allows the parents to be seen as, and respected as, parents and to feel they are contributing something useful, and it is *not* therapy.

In one of the early Kidstime workshops a group of children between ages 5 and 8 wrote and performed a play about a mother with mental illness. Sean, the elder son of Kate, played the mother, and an 8-year-old girl played the child. The child pleaded with the mother to get up to "make my breakfast . . . 'cause I'm hungry." The mother said she was too ill to get up and that she would remain so until she had a new supply of her "blue and red tablets," which she had run out of. The child telephoned the "doctor," who said he was too busy and suggested calling the "nurse," who in turn asked if there was not someone in the family or a friend (all played by children in the group) who could help. The friend said she would "try to come later," but suggested that the child ask the pharmacy. The child went to the pharmacy, and the "pharmacist," although saying the child was "too little," said she knew the child's mom and gave the child the drugs. When the child returned home, she could not rouse her mother.

She eventually realized that her mother was dead and acted out a powerful crying scene until Sean rose from the bed with a grin.

* * *

Perhaps not surprisingly, many of the professionals and some of the parents who were part of the group were shocked by this drama. There was conjecture about whether Sean, or one of the twins, had witnessed his or her mother taking an overdose, and it is likely that someone had. But as we all discussed the play later with the children, we realized an important function of the plays. They did not necessarily represent what the children had actually experienced—although they sometimes did for some children—but did represent what nearly all the children had thought or feared at some time. The drama then allowed the children to articulate such fears as a group and begin to "put them in their place." In this particular drama we also realized that we were seeing an artifact of the confused ways in which some children had been told about their parents' illness. Because the word "illness" had been used, but no real attempt had been made to explain the nature of mental illness, the children had applied their own logic about modern attitudes to medicine, which could be caricaturized as "If you don't get your treatment, you'll get worse and maybe die." This highlights the need for professionals who talk to children to examine their language and consider how children of different ages may construe different words and concepts—such as illness, medicine, and the like. This subject is addressed in the group exercises for professionals outlined in a later section.

What follows are some guidelines developed by the Family Project to assist professionals from a range of disciplines in talking with children about a parent's illness.

GENERAL POINTS

Many professionals from all disciplines are nervous about talking with children. They can be worried about upsetting a child or making the situation worse for him or her. However, as already discussed, it is not only important but may also be prophylactic to encourage children to discuss their experience of having a parent who has a mental illness.

Children often sense that adults, especially busy professionals, are rushed or short of time. As a result, children may be less likely to confide their worries or fears. Therefore, in talking with a child, it is very important to allow a reasonable amount of time—say 45 minutes to an hour. Make sure to have paper and colored pens with you. Many children are able to think and talk more easily if they can also draw or play at the same time, and most children and young people find it easier to understand an explanation if it is illustrated with drawings and diagrams. Start by finding out what the child or young person knows or has heard about you, where you work, and what you do. Make sure the child knows your name and what you will call each other. It is also helpful to ensure that the child knows how to contact you in the future if necessary. Reassure the child that you will be able to visit his or her family to talk again, or that he or she may be able to visit you.

Naturally, the age of the child affects what can be discussed with, and explained to, him or her. Even children as young as 3 or 4 may have the ability to be quite clear and candid about what they have seen or heard. Alternatively, they may be fearful of speaking because of concerns about their parent's safety. Or a young person who is, say, 12 years old may be very clear about what has been happening to his or her parent and its effects on others in the family, but may, out of loyalty to the parent, try to avoid telling what has been happening. This can be particularly problematic in "lone-parent" (or single-parent) families. In any case, ensure that what you say is simple, direct, clear, and straightforward.

Tell the child that the discussion is confidential and that you will share with others only the information that he or she agrees upon (i.e., it is private, not secret), unless something comes up that suggests he or she or any other person could be at risk of harm. Explain that if this should happen, you will talk to the child about what needs to be done—for example, if someone else does need to be told for the safety of the child or the parent. With all children, but particularly with adolescents, it is important to convey respect and to be clear about the limits of confidentiality

To engage with a child or young person, it is important to demonstrate a genuine interest in the child and his or her life as a whole, rather than in just the child as a source of worry and concern. Try to avoid "problem-focused" conversation as much possible, particularly at the beginning of the conversation (Cooklin, 2004). When you bring up the parents illness, a good starting point can be to ask the child or young person what he or she already knows or what explanations he or she has come to by him- or herself. Avoid the temptation to talk about what you believe are the child's sources of distress and worry, because you may not be right and it is best for this information to come from the child.

It is especially important after you have said something that you listen carefully to the child's response and are willing to discuss this response with the child and clarify his or her point of view before moving on to the next point.

By the end of the discussion, check to be sure that the child's understanding of his or her parent's mental health problems (or situation) is close enough to what you were trying to explain. Like adults, children are unlikely to be reassured by false optimism. Therefore, invite and take seriously any questions from the child or young person. If you are asked a question for which you do not have an answer, be honest and say so, but say that you will find out, and then do so. It may be that no one has an answer—for example, as to how long a mother or father will be in the hospital. In this case, be honest, but discuss the likely possibilities.

Toward the end of the discussion, or as a way of summarizing and ensuring that the child understands what has been said, it is useful to help the child or young person to construct a "pros and cons" list about any decision or choice—however small—that he or she can make.

SPECIFIC GUIDELINES

1. *Allow enough time, and do not rush either yourself or the child.* This is necessary in order to demonstrate to a child or young person that you are interested in him or her—in his or her skills, interests, and life—rather than just in problems.

2. *It can help to use a quiet, visual game.* The Squiggle game was originally developed by Donald Winnicott (1971b). This is an interactive game that can be played between an interviewer and a child. The interviewer and the child both draw a "squiggle" (an uncontrolled small scribble—best done with the eyes shut), and each invites the other to complete it into a drawing. This can be useful in engaging a child in a more collaborative mode of response or in eliciting certain skills and/or preoccupations of the child. Some children will, however, have their own favorite game that they will want to teach the professional. However, whatever the game, it is important to try to keep the atmosphere as calm and controlled as possible, so that there is the possibility of conversation, for example, between turns.

3. *You do not need to use a "special" voice. Be yourself. Speak in a simple, straightforward manner.* It is particularly important to be simple and straightforward in what you say and ask. Children of parents with mental illness may have been having to try to understand very complicated or confusing kinds of communications, and often have had to guess at what a parent really meant. They may then be particularly sensitive to professionals who are not clear and candid.

4. *Follow the topic chosen by the child, and return to your topic in a few minutes.* Try to hold in your mind the important issues about the parent's mental illness that you think the child or young person needs to understand. You can thus allow the child to divert you—often repeatedly—and you can then return to the topic when a suitable space allows.

5. *Listen carefully to what the child says, even if it seems irrelevant.* Some children and young people may engage you in complex and convoluted stories, which you may at first feel are off-track or irrelevant. Although it is important to keep in mind, and not forget, the key issues you need to discuss with the child or young person, if you follow the child's thinking you may find a more appropriate opening for the discussion.

6. *Beware of being patronizing or lecturing, but remember you are trying to help the child understand very difficult matters.* Discussion between adults and children often involves the adult telling the child things or asking questions about which the adult already has the answer. The child may then feel that he or she has to guess what answers the adult is seeking. The important need for the discussions highlighted here is for the professional to invite the child to offer real differences of opinion as valid subjects for comment, debate, or even argument.

The following nine points may be helpful to the professional who is relatively unfamiliar with discussions with children and young people. However, it is only one possible guide and should not be allowed to undermine successful practices already used by particular professionals or other approaches that are more in keeping with the professional's personal style (see Aldridge & Wood, 1998; Brown & Dunn, 1992; Cooklin, 2001; Dowling & Gorell Barnes, 2002; Feeny, Eder, & Rescorla, 1996; Jones, 2003; Minuchin & Fishman, 1981). Some of the following points were introduced earlier.

1. *Emphasize the child's positive abilities and interests.* Begin by focusing on conversation about the positives, the child's abilities and interests. Start with a genuine interest in him or her as a person, a particular toy or book the child is carrying, or even a particular T-shirt logo. However, beware of forced jocularity and assumptions. Do not make assumptions about what the child may be interested in, as can sometimes happen when professionals are anxious; for example: ". . . So which football team do you support?" It's better to say something like, "What kinds of things do *you* like to do when you don't have to think about these grown-ups?"

Moreover, rather than presuming, by showing empathy or sympathy that the child may not have invited, it is better to adopt a stance of congratulating the child on his or her achievements in a nonpatronizing way. So rather than saying, "You must have been very worried about your dad being ill," it might be preferable to say, "How did you find a way to manage all these situations so well?"

Try to engage the child in a "thinking" conversation in which he or she is actively engaged with you and actively listening and contributing. Finding a topic that engages you both can take time, especially with young children, but making the effort to do this will enormously help to engage the child and make the process meaningful for him or her. It may also be important to acknowledge any possible benefit the child or young person thinks he or she has gained from the experience of the parent's mental illness.

2. *When introducing the subject of mental illness, be careful not to make assumptions about how the child or young person may have experienced it. Be "behind" rather than ahead of the child.* Resist the tendency to

try to guess at, or even suggest, what the child is thinking or feeling about the situation in his or her family. It is preferable to ask a child to explain, and if necessary to acknowledge that you do not understand something he or she is trying to express, and then to ask the child to help you. So, rather than saying, "You must have been very sad/worried/frightened to see your Mom looking so low/upset/frightened," it might be preferable to say, "So when you saw your mom like that, what was it like?" And if the child says, "I don't know," or "Nothing really," it may be better to take a step back from the child by asking a less personal question, for example, a binary- or multiple-choice question. Such questions can be easier to answer, because they do not face the child with so much anxiety about what you are seeking or will accept. For example: "Well, was it the sort of thing that might make a daughter/son more angry, more sad, or more worried?" (See below.)

3. *When you are asking questions, frame them so that they are easier for the child to answer than to not answer or to answer "I don't know."* Children worry about giving "wrong" answers to adults, and they often assume that there is a correct answer to a question that the adult wants to hear. A child who is anxious or frightened may worry that he or she will give the "wrong" answer to an open-ended question, and particularly to an open-ended question that does not give any clues about the sort of answer that is expected. Help by asking binary- or multiple-choice questions, or by making statements that invite one of a number of responses, as these suggest a range of anticipated responses and may be easier to answer, as the child can select one of the choices, reject all of them, make a different point, or even disagree. If, presuming that a child wants to share his or her thoughts and feelings, you ask an open-ended question, he or she may face more anxiety; for example: "So, what did you think [or even more anxiety provoking, "What did you feel?"] about your mom not getting up to make your breakfast?" It might be easier for the child to answer: "When your mom didn't get up to make your breakfast, do you think you were more worried about her, more angry, or just very hungry?"

4. *Children and young people may be able to respond to or recognize an idea or experience that is described as a generalization, when they may find a personal question too anxiety provoking.* So rather than saying, "You must feel very responsible for your mom's upset," it may be preferable to say, "Did you know that many children and young people in this situation seem to feel as though they are responsible for caring for their parents, rather than the other way around—it's strange, isn't it? [perhaps adding] Of course, that may not have happened to you, but it does happen to lots of children."

5. *Make no interpretations or presumptions about a child's experience, but ask.* The preceding points have highlighted the importance of not making assumptions or interpretations, because, given time, patience, and a demonstration that you are prepared to wait for the child to think and

speak, rather than "thinking for" him or her, children of all ages will attempt to articulate even their most complex ideas.

Professionals who suggest the meaning of what the child is trying to say may stifle the child's own attempts to clarify his or her thoughts. However, if a child consistently talks about, or draws repetitive images and seems to be stuck, you might say, "That these pictures have given me a funny idea," and ask if he or she wants to hear about it.

Occasionally, a child will firmly reply, "No," in which case this answer should be respected. If the child says, "Yes," then you could say, "You have drawn a lot of pictures of what looks to me like a mom or someone else getting hurt, or very upset [whatever it is], so they do make me think some things. Do you want to know what I think?"

If the child says, "Yes," you could say, "Well, they make me think that maybe you think this could happen to your mom, or that you are worried that it might."

If he or she says, "No! I just drew them because . . . ," you should probably say, "Oh—right. . . ."

But sometimes the child may say, "Well, it has happened to my mom." Then it's important that you do not seem surprised or shocked, but say something like, "Is that something we could talk about together, or do you want to keep it private?" If the child does insist it should be private, despite having slipped it out, then you may need to say, "OK, that's for you to decide, but imagine you did tell me about it, what do to you think might happen then?" in order to convey that it would be OK to talk about it.

6. *Challenge the child's assumption that he or she must comply with the adult's expectations of him or her.* Encouraging a child not to follow what he or she presumes is expected may go against some of our preconceived views of children's ideas and against children's expectations of how they will be expected to behave. It requires a change of tone in the conversation with a child, and often a change in how we think about children.

Why is this change important? Because unless a child or young person feels that he or she has the right to have his or her own opinions, and that he or she will be listened to and his or her views respected—even if you do not agree with them—then the child or young person will not be able to engage with you in a "thinking" manner. The child's main need is to be helped to think about a parent's mental illness with a concerned adult.

One way to approach this is to seriously encourage a child to tell you about something he or she is better at, or knows more about, than you, and then both question and respectfully debate his or her point of view. The subject could be something as simple as how some girls think boys are a disruptive influence in the classroom. For example, if the child is a girl, you could ask, "Do you think you will never want boys in your class?" And if the answer is "yes," you could add, "But some girls do seem to change their minds about this when they get older . . . have you noticed that? . . . Why do you think that happens . . . ? etc."

7. *Encourage challenge and contest (but not combat). The conversations may appear both silly and playful, but can be serious underneath. Avoid insincere or forced jocularity.* This follows from the need to demonstrate to the child that he or she can disagree with you, as indicated earlier, by gently and with good humor encouraging debate with the child. Do not be fazed when the child disagrees with you. It is also important that you resist the temptation to either try to win an argument or to humor the child in a manner that could appear to be patronizing.

The goal is to help the child think, not to elicit feelings—a child will show what he or she feels as and when he or she chooses.

If a child can begin to reflect on the topics discussed with a professional, he or she will have often achieved the first step in mastering his or her worries about whatever the issue is. For example, if the child is contemplative, saying something like "So maybe my dad just thinks everyone is against him 'cause he always thinks the worst will happen," it may help to encourage the child's internal debate, for example, with "Could be . . . or I suppose maybe there could have been some times in his life when he *did* feel picked on. But did you know that some illnesses in the mind can make people feel that everyone is against them?"

What does *not* usually help the child is for the professional to be a detective, trying to "get to the bottom of" what the child feels about it all. The child will show rather than tell what he or she feels when he or she chooses to.

8. *Try to find some aspect of the situation about which a child or young person can make his or her own choice.* Children and young people may have felt totally helpless in the face of a parent's erratic behavior, or may have had to be totally in control. Either way, a hospitalization of a parent, a change in care arrangements for the child, or other sudden changes resulting from the parent's illness, may leave the child or young person feeling confused, lost, and desperate. It is likely that many decisions were made without the child's being consulted. If the professional can recognize this and find some—however small—decision in which the child or young person can participate, it may allow the child or young person to feel less helpless, and as a consequence, he or she may gain greater mastery over him- or herself. If there is a significant decision to be made, such as where the child is to stay during a parent's hospitalization, the construction of a "pros and cons" list with the child can be very useful. This allows the professional to offer suggestions for the two columns, while the child actually retains some mastery over the decision.

9. *Use drawings or other visual aids and/or a quiet visual game (see the Squiggle game referred to earlier) with a child or young person, to explain the illness and to understand the child's perspective.* Most children and young people are helped by being able to draw their own images of what is being explained (a depiction of the brain and nerves, a diagram to link the body, mind, and feelings, etc.) so as to gain sufficient mastery over

an idea for them to be able to consider it. Rowdy play may not be helpful to a child or young person. The child may use this simply to try to keep distressing thoughts or feelings at bay and may then become overwhelmed by the same thoughts or feelings later. If you allow a situation to become rowdy, children may actually feel less safe, despite the fact that they are the ones creating the upset.

It is also important that games do not take over to such a degree that there is no real possibility for a child or young person to talk, and it may be the professional who is most anxious about what needs to be discussed.

TEAM EXERCISES

Multidisciplinary teams—particularly teams working across different agencies—may find the following exercises useful in thinking about how to discuss the mental illness of a parent with a young child.

1. In groups of four, using not more than eight sentences, devise an explanation for an adult (a) patient and (b) relative about schizophrenia. Work out the actual words and phrases you would use; then share them with the team and discuss.
2. In groups of four, devise an explanation to (a) a 5-year-old girl and (b) an 8-year-old boy that her/his mother has to go to the hospital for an operation for the removal of a benign cerebral tumor, in which there is a significant risk to life.
3. In groups of four, repeat Exercise 2, but replace the explanation of the mother's operation with an explanation of schizophrenia, modified from Exercise 1.
4. Do a role play either in groups of four or with the team as a whole and repeat the preceding exercises. In each case choose one member of the staff to play the child, one to play the professional, and two or three to act as observers who take notes. Be sure to allow plenty of time at the end for discussion, especially of the participants' experiences of the exercises.

Discussion Points for the Team

1. What will the word "illness" mean to a child? What are the possible consequences of how a child might understand this word?
2. How might this have affected a child's thinking in, for example, the film (originally produced by the children in a Kidstime workshop), in which the mother dies because the child cannot collect her blue and red tablets in time? (see the report on Kidstime workshops, featured in the film *Being Seen and Heard* [Cooklin, 2004]).

3. Make a list of other words and terms that you have heard being used by mental health, child mental health, or social services professionals. Discuss how these words and terms might be interpreted by children of different ages.

4. Some children plead that parents should be hospitalized earlier. Discuss the possible implications as well as possible solutions for services.

Finally, helping a child find a way for his or her voice to be heard may need to include helping the parents to reestablish some working authority, so that a more "parental" voice of the parent can be heard, as illustrated in the following example.

Chrysoulla, age 36, had two children, Alexei, 16, and Doulla, 10. She was the only daughter in a Greek Cypriot family of older sons and had always acquiesced to her father's wishes. She married a man of her father's choice, but this proved disastrous. She returned home to live with her father on the top floor of a large, terraced house in North London. She did not complain. However, she increasingly withdrew into her room, keeping the curtains drawn, and would not go out of the house or even leave the top floor. She said nothing and, eventually, as she was neither speaking nor at one point eating, she was hospitalized in the local psychiatric unit. The staff members there believed that she was probably experiencing hallucinations, but as she rarely spoke, they had no direct evidence of this. A cycle of admission, discharge, and readmission went on for 2 years. Although her son, Alexei, had begun to make friends outside the family and soon found work, Doulla seemed to feel increasingly caught between her grandfather's expectations and her mother's world.

In this section of an interview with Doulla, her older brother, her mother, her uncle, and the aunt who had referred her, I am exploring the issue of whether her mother, Chrysoulla, is able to have a voice in the upbringing of Doulla.

AC: So, how do you work it in your house? Supposing your mom tells you one thing and your granddad tells you another? Does that ever happen?

ALEXEI: (*to Doulla*) Well, you told me that sometimes granddad says you've got to be in at 5:00 and Mom says it doesn't matter.

DOULLA: Yes, well, that does happen sometimes.

AC: So when it happens, which one do you listen to?

DOULLA: (*Grins.*) Well, it depends on which one I agree with.

AC: Oh, I see. That's the system. You choose which one fits what you want and you agree do what that one says.

DOULLA: Yeah.

AC: (*to Chrysoulla*): So which one do you think Doulla should listen to, you or your father?

There is a silence. I am not sure if Chrysoulla will answer, as she often does not. The tension in the room begins to mount. After a longish pause, Chrysoulla eventually answers, "Both of us."

AC: Well, that sounds good. Providing you both agree. But, Chrysoulla, whom do you think she should obey if you and your father say something different?

Chrysoulla surprises everyone by answering immediately, "She should listen to me." Doulla has meanwhile become silently tearful, which at first appears not to be noticed by any of the family.

I pursue this with difficulty but eventually achieve some clarification with the daughter:

DOULLA: I didn't expect her to say anything because she doesn't. . . .

AC: But she did just now, didn't you hear her?

DOULLA: Yes.

AC: In fact, she was quite clear; she said that when my father and I say something different I want Doulla to do what I say. So how did that grab you?

DOULLA: Well, that's fine, but she never says it to my granddad.

This interchange led to other members of the family supporting Doulla in achieving some clarification as to whom she was to be answerable, and in fact seemed to have the effect that Chrysoulla became more vocal, at least where her daughter's welfare was concerned.

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Thus, quite small elements of parental behavior may be experienced as a great relief by children and may allow them to begin to hear a parental voice, which is less a source of worry and even the beginning of a source of comfort.

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