Part I

Basic issues
What we want from adult psychiatrists and their colleagues: ‘Telling it like it is’

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Children and young people want professionals to listen to them, to talk to them and, above all, they want to be recognized as important to the parent they live with.

In November 1999 a small group of young people involved with Barnardos Action with Young Carers (AWYC) were invited to take part in a conference launching the report ‘Keeping the Family in Mind’ (Göpfert et al., 1999; Mahoney, Chapter 23). The project, like other Young Carer projects, provides a service for children and young people who live with someone with a mental health problem, many of whom take on caring roles and responsibilities. All of the young people who participated care for a parent with mental ill health and receive support from staff at the AWYC’s project. We know from research and consultations with children and young people that they value being listened to and drawing upon their own experiences (see Cooklin, Chapter 21). They have some very important messages for professionals and policy makers.

Introduce yourself, tell us who you are and what your job is

Young people report that they are often ignored by professionals. They are not given information about what is going on in the family and who and why professionals are visiting. The way in which professionals deliver their service to a family can have a direct effect on other family members.

Have you any idea what it feels like for a complete stranger to come into your home, ignores you and then blames you for your home situation?

Sometimes I remember coming home from school and walking into our living room to find someone I didn’t know sticking a needle into my mum. They never introduced themselves but just continued to do what they were doing.
Tell us what is going to happen next

Young people do not always know where to go for services, get information or how they can be included in decision-making. They are unfamiliar with how agencies work and professionals need to take time to explain what is happening or the process and procedure required to make things happen. This helps allay anxieties and gives recognition of the young person's role within the family.

All the professionals would visit whilst I was at school. I would come home and her medication would have been changed. I was the one who had to make sure she was taking her tablets but no one explained what they were or what they were for.

Give us as much information as you can

Children and young people want to understand and make sense of their parents' ill health. First, it is important that the information given is age appropriate. Second, this can be written or given verbally by professionals who have some knowledge and understanding and are able to answer young people's questions.

I feel if I had had more information about my mum's illness at the time, it wouldn't have been so difficult for me. I might have been able to understand why she cried so much and why she said and did such strange things. I might not have worried so much that I would become like her.

Talk to us and listen to us — remember it is not hard to speak to us, we are not aliens!

Children and young people want to understand and be part of decisions made about their family. They want to be respected, included and acknowledged. Article 12 of the UN Convention on the Rights of the Child states children have a right to be listened to and have their views taken into account on matters that affect them.

I remember calling my mum's social worker and asking her to come to see my mum because she had started to become slightly manic. She came three hours later and by that time my mum's mood had changed again and she was calm. My mum's social worker came in and sat down. She didn't ask me what had gone on, she just asked my mum how she felt and my mum said 'fine'. By 3 a.m. the next morning the police and ambulance had been called by neighbours. My mum was taken to hospital and put on a 6 month section [a compulsory order].

Ask us what we know and what we think — we live with our parents, we know how they are behaving — ask us!

The recognition of the role and support given by other family members needs to be valued, whilst acknowledging that without accurate information children and young people may not talk freely for fear of being separated from their parents.
‘Telling it like it is’

Children and young people are an important source of information about their parents’ health. It is a two-way process. They can also assist professionals!

Before my mum went into hospital, it felt like we were hiding and keeping the situation in our family, locked away. When she went into hospital, it was like an explosion. There were lots of people around us. I felt frustrated and confused.

Keep on talking to us and keep us informed — tell us it is not our fault

If information about what is happening is not shared then, for some people, this can leave them feeling guilty and to blame for their parent’s illness. The young people are often given the responsibility for caring, but are not given the opportunity to participate in the decision-making.

One time the doctor came to see my mum at home. I opened the door to him and tried to tell him that my mum wasn’t well. He told me he wanted to speak to an adult in the family. There was only me and mum and she was ill in bed upstairs. He went to see her and when he came back down, he handed me all her tablets and told me not to let her have any of them.

Tell us if there is anyone we can contact

The provision of information and access to services is an important factor in supporting children in the family. Professionals need to make themselves aware of ways in which they can assist supporting the young people and their families and other services available in the area.

Most of my teachers understood my reason for being away from school, but some thought that just because my mum was depressed enough to lie in bed and cry all day or be manic and throw everything from clothes to furniture out of the window, I still did not have reason enough to miss their classes, although I did try my best to get good grades and keep up to date with lessons.

Please don’t ignore us, remember we are part of the family and we live there too

A recurring theme from young people is that other family members need support. Changes in practice, that cost nothing, can make a significant difference to the lives of these children and young people.

Two people arrived and sat beside my mum and dad. They did not introduce themselves to me even though I was in the same room. I heard them talking about my mum. It was as if I was invisible. I was glad when they went.

Previous personal accounts (Roberts, Chapter 20; Marlowe, 1996) also told of acts of thoughtlessness by professionals. Children who had witnessed their parents’
disturbed behaviour, added these experiences to their feelings of disregard. From the professional's point of view, these encounters often arise unexpectedly, either through routine interactions with a client with whom they already have a relationship, or while undertaking emergency duties without a previous relationship with the client. An individualized focus draws a boundary around the professional–client relationship which excludes the children, and therefore it is as if they are not present.

However, there is some evidence that some professionals use these momentary encounters to connect with children. Approved social workers in the UK have a statutory role under the Mental Health Act 1983. They must undertake a social assessment and consult the closest relatives, and explore the possibility of any alternative to a compulsory hospital admission. Sometimes children are present, and some approved social workers make a point of explaining their role and actions to children, although a minority thought that they were not allowed to speak to the children (Webster et al., 1999). The social workers most likely to speak to children were parents themselves.

Many booklets are now available to help professionals explain mental illness to children (Falkov, 1998; Sobkiewicz, 1996a, b), some of which emerge from local initiatives (Joint Consultative Committee, 1999). They provide formulae for adults to develop a personalized story and for groups in which children can share experiences. With minimal notice, it is possible to create a context in which children feel contained, such as when helping children in a residential setting deal with parental suicide (Ward, 1995).

Conclusion

These messages reinforce the view that the direct involvement of service users and their children is essential to improve the quality and range of support to families living with mental ill health. Family members have diverse needs, and the impact of living with mental illness must be recognized, and risks assessed. Many of the necessary changes are possible and some will demand resources. But what the young people highlight is the need for more fundamental changes of attitude and approach from services.

REFERENCES

7 ‘Telling it like it is’


Introduction

Because individuals and families seek relief from psychological distress from a number of different sources, confusion can arise as to the specific role of one professional versus another. Tugs of territorial war often exist among psychologists, social workers, child psychiatrists and adult psychiatrists, to mention only a few of the players. Each profession is armed with its own specialized weaponry of psychological interventions and rival factions not infrequently claim superiority. To some degree this has become a battleground for the distribution of limited resources. Statutory issues such as prescription rights cause bitter interprofessional disputes. The roles of mental health workers are not always sufficiently clearly delineated, nor can they ever be because human suffering knows no clear borders. So the professional field is rife with tensions, splits and competition while the needs of patients or service users go, at times, unmet. In our experience and in the opinion of others (Consumers’ Association (UK), 2002), when the expertise of service users is recognized and when they are given a degree of power in the way services are designed and delivered, professional competition is reduced and interprofessional collaboration grows.

This book focuses on services for individuals with mental illness who are parents. In many systems of mental health service provision, the identity of the patient as a parent does not receive sufficient recognition (see Göpfert et al., Chapter 5). This is true irrespective of the patient’s diagnosis or type of service provided and, therefore, clearly reflects deficiencies of service design, training and professional role identity. As one family put it succinctly in one of our research projects: ‘Psychiatric services are excellent when it is a question of treatment of symptoms but absolutely useless when it comes to family issues or anything beyond the symptoms of mental illness’ (Göpfert, pers. obs.). It is with this consideration in mind that we outline the role of the psychiatrist and highlight pertinent issues that arise when a patient is a parent.
9 Parenthood and adult mental health

Perspectives of power and hierarchy in mental health services

For decades the power of the doctor resided in the particular expert knowledge and clinical skills that she or he was presumed to have. This is now increasingly being eroded, but for the time being the doctor still has a dominance among other health professionals that is based on the role of diagnostician and prescriber of medical treatment, and when all goes well, is validated by the quality of training and competence. In terms of the dynamics of the organization, this is a powerful position, containing anxiety for both patients and carers, and for other mental health professionals (see Göpfert et al., Chapter 5), and shouldering risks that other mental health professionals might not yet be ready to accept. Therefore, for now, the medical member of the multidisciplinary mental health team may hold a particularly influential position that can define both the shortcomings of any service, but also its strengths. The mental health professional who carries out an assessment and decides on treatment has the power to allocate or withhold resources from the patient and the patient's family, and therefore the patient is in a somewhat dependent role.

The role of the psychiatrist attending adult patients is, first and foremost, to assess the complaint the patient presents and make a provisional diagnosis. The psychiatrist then rules out other possible diagnoses, considers comorbidities, and initiates a treatment plan. The prescribed treatment is subsequently monitored, both for effectiveness and for freedom from unwanted side-effects. The psychiatrist also provides the patient with information about the diagnosis and the treatment and offers a prognosis on how soon the patient is likely to be free of the presenting complaint and ready to resume former activities. Since psychiatric problems invariably impact on those close to the patient, psychiatrists need also to make themselves available to family members. All patient–psychiatrist exchange happens in the context of a relationship, and the quality of that relationship, or therapeutic alliance, determines outcome to a significant degree.

There is a substantive body of evidence that shows psychiatric symptoms arise from early experience. That early experience is important to elicit because taking it into account will make treatment more successful. For instance, there is some emerging evidence that links the symptom of hallucinations in a proportion of people seen by adult psychiatrists to an early history of childhood sexual abuse (Bentall, 2003). On the other hand, hallucinations may be associated with traditional cultural beliefs in supernatural powers. Such considerations are of extreme relevance to treatment. Therefore, as part of a comprehensive assessment, psychiatrists ask their patients not only about symptoms but also about developmental history, ethnicity and culture, and religious faith, about the type of work they do, about financial security and medical status, about social relationships, where and with whom they
live, and whether they have children at home for whom they are responsible. Surprisingly, the question about parenthood is often not asked or not recorded in the medical chart (Hearle et al., 1999; White et al., 1995). Especially important in this context is the ascertainment of single parent status and finances because these correlate strongly with the adequacy of parenting (McKie, 1993; McLanahan & Sandefur, 1994; Munroe-Blum et al., 1988). Because psychiatric illness is, to a certain extent, linked to teenage pregnancy which, in turn, confers potential harm to children (Kessler et al., 1997), the age at which the patient became a parent is important to know. Another important variable to monitor is the presence of domestic violence (Royal College of Psychiatrists, 2002), as this is common and of relevance to both the mental health of the parent and the healthy development of children.

Some psychiatrists argue that, as doctors, they should mainly be attentive to disorders of somatic origin, defining psychiatry essentially as neuro-psychiatry. Contextual and psychological issues, in their minds, belong to the domain of other professional groups. This reinforces the very issue of specialization which so clearly is one of the major barriers to appropriate service provision for families when one or both parents has a psychiatric disorder (Hetherington et al., 2002) (Hetherington & Baistow, Chapter 26; Falkov, Chapter 27). It raises the old nature vs. nurture debate, with physicians attending to nature and non-physicians to nurture. In our opinion, the current evidence clearly supports the view that the effects and aetiological significance of genetic and neurophysiological factors can only be fully appreciated in the larger context not only of the whole person, but also of interconnected family and social networks (Leff, 2001; Lerner, 2001). For instance, adopted-away children at genetic risk for psychiatric disorder are persistently more likely to receive negative parenting from their adoptive parents than children who are not at risk. This suggests that the behaviour of these children elicits a negative response from their environment (O’Connor et al., 1998). At the same time, significant aspects of parenting patterns create and reinforce enduring personality features in children as they grow into adulthood (Casi et al., 2002; Kendler 2001; Moffitt, 2002; Plomin et al., 2001). Having a depressed parent is a strong risk factor for depression in children (Beardslee et al., 1998) and in adults (Nomura et al., 2002). Psychological intervention can help these children (Clarke et al., 2001); so do family interventions. Psychological interventions alter biology and biological interventions alter psychology (Fishbein, 2000; Leff, 2001; Wykes et al., 2002). Both genetic and shared environmental factors are essential ingredients of human development with varying and sometimes surprising effects in terms of directionality, interaction and power (Plomin et al., 2001; see Reiss et al., 2000 for a detailed analysis of the interconnectedness of genetic, shared and nonshared environmental factors in human development).
11 Parenthood and adult mental health

Children of mentally ill parents are being actively recruited into research studies specifically because they are known to be at risk. It is ethically important that they be viewed not only as subjects for research but as members of a family that can benefit from sophisticated understanding and intervention. Mentally ill parents may be in double jeopardy, attempting to raise children who are 'difficult' children because of genetic predisposition while, at the same time, struggling with their own mental health problems (Azar, 1997). The developmental lags of the children may be inappropriately attributed to poor parenting when, in fact, the parents are coping as best they can with temperamentally difficult children. They need help and understanding rather than misattribution.

For the psychiatrist, professional competence requires fluency in working in both the psychological and the biological domain, although personal preference will always dictate the specific focus of one's work. Psychiatrists need to be up-to-date with current developments in the biological understanding and treatment methods of their field. Equally, they need to be competent not only in the delivery of psychological treatment to individual patients but also in family intervention. This is especially necessary as public health considerations impose increasingly stringent requirements of preventive practice in mental health service provision. Since a psychiatrist is often the only professional with statutory responsibility for treating a mentally ill parent, considerations for the well being of the children of that parent fall squarely within the psychiatric remit. Among clinicians, they are the one professional group that holds the key for effective prevention and intervention not only for the parents but also for their children.

Why does it matter?

Some psychiatrists still argue that proportionally few of their patients are parents. The actual proportion varies from setting to setting but it is reasonable to assume that as many as half of all patients seen in adult facilities are parents with children at home (R. Haigh, pers. comm.; Poole, 1996). Although the bulk of the literature in this area deals with mothers with mental illness, the responsibilities and requirements of parenting, i.e. the social role of parent, are the same for fathers, except for the specifics of pregnancy and lactation (Abosh & Collins, 1996). First and foremost, it is the far-reaching consequences for children that make questions about parental status important to ask of all adults who seek help from psychiatrists. This is a unique opportunity for preventing problems that may lie ahead for these children and must not be missed. These families may have no other contact with services.

Additionally, for the sake of the adult, a psychiatrist–patient relationship must also go beyond symptoms to involve the whole person, including the person's