

Young Carers, young Victims, or young Survivors?: impacts on, and responses of children of parents with mental illness

Introduction

It is timely to stop and think what is meant when statistics and descriptive narrative about young carers are cited.

Whilst it is necessary to define children in this situation as young carers – because some resources are identified for this group – the term itself is problematic. It tends to sanitise the often quite unacceptable and intolerable demands being made on some children and young people. Most children and young people who have a parent with mental illness will not think of themselves as carers, even if they are lucky enough to attend a ‘Young Carers’ programme. They may think of themselves as surviving, as lonely and isolated, and of suffering all the common experiences listed below. But because of the nature of mental illness, and the unlikelihood that their parent will actually acknowledge that they have become the carer rather than the converse, they are unlikely to see themselves as having such a role which should at least command much respect. As a result many children and young people will be left vulnerable to sometimes extremely damaging and distressing situations. For this reason it is critical that Young Carers Assessments – a statutory requirement of health and social care providers, but currently carried out in a systematic manner by only a handful of health providers – are an essential requirement if there is to be any chance that the particular needs of

individual children and young people can be even partially met. As identified below this has very serious consequences for the prevention or otherwise of mental illness in these children and young people later in life. This article will define some of what is known about the impacts of parental mental illness on children and young people, their responses, what they **say** they need and want from professional services, as well as some suggestions for how professionals may respond.

The number and nature of the risk

Albridge and Becker (2003) have provided the most reliable estimates and conclude that between 6,000 and 17,000 children in England and Wales will be caring for a parent with mental illness at any one time. However even these estimates are fraught with difficulties arising from a combination of loyal children’s reluctance to acknowledge what is happening at home, combined with the failure of most current services to ask children of parents with mental illness about their experiences. Aldridge and Becker have also concluded that about 170,000 children are caring for a parent with physical or mental illness, and that it is likely that about one third of these are parents with predominantly mental illness. On that basis about 55,000 to 60,000 children will be affected. However they have also extrapolated figures from a number of different studies to suggest that about three million children under the age of sixteen are being significantly affected by a parent’s mental or physical illness, and therefore about one million are affected by mental illness. The extraordinary spread of these figures is, however, only an indication of the lack of knowledge about, as well as the previous serious neglect of, these children.

What is known from studies of Aldridge and Becker, as well as from what we have learnt from talking to children ourselves (the team of the ‘Kidstime’ workshops, described below), is about the impact on these children. In the USA the National Co-morbidity Survey USA (Nicholson et al 1998, 1999) showed that 68% of women with mental health disorders are parents, compared with 57% of men. Similar figures are reported in the UK (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, compared to 20-25% risk in the general population (Beardslee, 1983)

Of very serious import have been the findings of 'part 8 reviews' in the UK 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 inter-agency 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 children's experiences prior to their premature deaths. The training manual and reader on working with mentally ill parents and their children, published by the (UK) Department of Health (ed. 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 behavioural development of children.

These findings were confirmed by Aldridge and Stuart (1998) who reported a 'befriending project' for children of parents with schizophrenia. 73 per cent of the children reported serious distress resulting from their parent's illness – the main complaints reported being a sense of being ignored, pressure to be 'good', false maturity, and fear of family breakdown. Similar complaints were reported by Mackereth et al (1999) in which the young people interviewed reported a lack of explanation of their parent's disorder, and a consequent sense of personal blame and responsibility. Weir (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... out of mind' continues to predominate". Furthermore Dunn (1993) found high 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 in adulthood, which as children they may have feared disclosing, suggests that there may be significant underreporting of abuse by children of mentally ill parents, 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 investigation leading to a film and training pack 'Being Seen and Heard' described extreme violence that they had never reported, and that had not been reported by neighbours, nor detected by the child protection services:

Helen was 17 when interviewed, and was only now living in a supported independent hostel. She had been returned to the care of her mother by her father when she was aged 10. The mother suffered from long term schizophrenia, would frequently beat her if she thought she saw Helen grin, would scream that she (Helen) was a whore, and had several times threatened to kill her.

Alison was aged 19 when she gave birth to her own twin babies. 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.

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In neither case had there been any professional intervention or explanation offered to the girls – only occurring in Helen’s case when she was placed in independent living at age 17, and in Alison’s case at age 18 when an enlightened Psychiatrist decided to investigate what was happening in the family.

A number of factors, particularly the presence of an alternative caring adult, can mitigate against these negative effects (Schachnow, 1987). Rutter and Quinton (1984) and Rutter (1987, 1990) identified a ‘capacity to appraise’ stressful situations, particularly through the availability of a warm, concerned, but relatively non-involved adult, as a significant protective factor and Cowling (1999) confirmed that the availability of one or more adults with whom the child can develop a supportive relationship is a key factor in a 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 – being an explanation which 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.

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 1985, 1994, 2004). They demonstrated that the children of mothers who had Schizophrenia, and who were subsequently adopted, had an incidence of schizophrenia that was similar to 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 taken into account they found that the adopted children had an incidence of Schizophrenia that was not significantly different from that of the general population. It suggests that good relationships and family environment can have a strong protective function.

Not all children with a mentally ill parent show evidence of significant harm, and some parents struggle hard to protect their children from the effects

of their own illness. As Kate, the lone parent of Sean (aged 6) and Alec (aged 5) said “It’s strange, mental illness...although you can’t really control it, when you have children you really do try to minimise 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 psychiatric hospital.

There are now a growing number of ‘Young Carers’ groups funded either directly by local authorities or via a voluntary body. These are often after-school ‘fun’ groups where children can have time out from home worries, do activities like swimming, skating, going to the movies, and sometimes talk either individually or in a group. Most of them do not involve the parents. The ‘Family Project’ in Camden and Islington, London is a project designed to introduce family thinking and training into the practice of a general adult mental health provider. The team joined up 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, including those who were or had been ill, as well as their spouses if they were still in the relationship, and the children. In fact it was 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 which they could offer to the children.

What eventually evolved over some four years was the following format. Parents and children – and the children and young people could be any age from 4 – 16 – would come monthly after school at about 4.30 pm. New families would be briefly met individually, both to explain the goals and format of the workshop, as well as 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 might 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. After this, the groups would split. The parents would meet in one group for about an hour, and discuss topics related to being a parent who is, or was mentally ill. The children would start with games organised by a children's drama workshop leader, and would then begin to construct stories, culminating in producing one or more short plays (of between 3 and 15 minutes), which we would then film. The whole group would then 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 applause by the parents to intense shared discussion of the issues portrayed.

For those who attend the groups regularly they have become very popular. Kate's son Sean was reported to have said to her "Thanks for having a mental illness Mum...I really love coming here". The group participated in the production of the 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 mental illness, their experiences of professionals and of in-patient units. In the second part it illustrates ways of talking with children and young people, both on their own as well as in the family. The 'Kidstime' workshops are also illustrated as a special project.

The following lists are extrapolated from discussions with children and young people over the past 5 years of the work of the project.

1. 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; e.g. one parent making demands which 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 parent's future as a couple (if there are 2 parents), for the future of the family, and about who will look after him/her
- Contradictory expectations, i.e. that the child be 'grown up' and 'a carer' at home, and a child at school.
- Rejection, harassment, and/or bullying by other children at school or in the neighbourhood
- Self-isolation, through stigma and fear of rejection

In addition a number of **other common effects on a child's life** have also become apparent:

- 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 have observed that **children and young people commonly respond to a parent's mental illness by:**

- Attempts to fill the care-taking space left by parents by taking care of parents and/or siblings. This can sometimes result in a child becoming dictatorial or bullying.

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- Self-blame and taking undue responsibility for the problems in the family or for the parent's illness
- Confusion about how to interpret their ill parent's behaviour, particularly in respect of the parent's anger. Confusion about whether it is the illness that causes the anger or if it is a result of something they (the child) 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 disassociation from the problem, particularly if another sibling is 'taking control'
- Violent and/or other self destructive behaviour
- Copying the parent's symptoms and/or behaviour, particularly in eating disorders

2. The needs and wishes expressed by the children and young people:

From a small study of 11-15 year olds, living with a depressed parent, Garly et al (1997) found that the children particularly wanted discussion about the following four topics:

Understanding the illness; including their own concerns, ideas about the cause of the illness, and access to information.

1. How to recognise the signs of an impending illness
2. Issues to do with hospitalisation
3. Advice about management of the illness; including coping with the effect on themselves as well as on their parent, perceptions of what is helpful to the parent, and recommendations for other children whose parents are depressed.

This is in line with the wishes expressed by the Children and young people we interviewed, who wanted:

- To have a frank discussion about their parent's illness so they can think about the situation more objectively, and 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 organised and what treatment the parent is receiving
- To be helped to recognise when their parent is becoming ill, to understand the behavioural 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 behaviour from an adult
- To know that their knowledge and experience of their parent's illness will be listened to and taken into account in terms of care planning
- To know that their contribution to the care of their parents has been recognised and respected
- To have daily life re-established
- To experience all the professionals concerned with both adults and children to be working together
- To have help and support with education, training, and employment
- To have recognition and acknowledgment of any positive benefits of their situation

The responsibilities of mental health staff

The problem about this group of children and young people is that their needs are the responsibility of 'everyone and no-one'. There is good evidence that children can emotionally survive extreme adversity providing they can understand what is happening to them (and as far as possible why), and that they have at least one reliable and non-partisan adult with whom they can affirm a more objective perception of the events effecting them. This is probably why the impact on a child with poorly developed language

skills may be more serious and more entrenched. The first need of these children therefore is for a convincing and understandable explanation of what is happening to their parent, what is likely to happen and why, the likely impact on their own lives, and what part they can play in their parent's recovery. This is much more important than any suggested form of counselling or other therapy for the children. Many children will actively – and often correctly – oppose offers of counselling, which they may perceive as placing themselves in a similar category to their ill parent. Thus it is the responsibility of local health and social care services to ensure that each child of a parent with mental illness has one or more opportunities for detailed discussion of their parent's illness, and this – if possible – needs to be linked with what the ill parent is willing and able to explain. If there are two parents who are active in a child's care then the well parent should be given advice about why explanation is important and asked to participate in the discussion with the child. Herein lies the problem.

These children will rarely present with serious behavioural problems. As a result they are unlikely to be known to the Children and Families sections of Social Services. Even if they are known to them, most of these social workers will tend to avoid much discussion of mental illness, claiming that it is not a subject that they themselves understand adequately, or has been addressed sufficiently in their training. Child and Adolescent Mental Health staff will also rarely see these children, as they rarely present with a level of symptomatology which would justify the use of their sparse resources. They may however be able to offer a valuable training resource to mental health and other staff undertaking this work. However many staff in Community Mental Health teams may not have been addressing the need for explanation to the children of their patients, only partly because of the size of their case loads. They have also been discouraged by worries about how to speak to children, uncertainty about what these children will understand, and what in any case to explain about mental illness.

What is clear is that someone needs to explain the illness to a child, and whoever takes on this

responsibility needs to consider in what context they will carry out this work. While I have referred specifically to explaining to a child, it needs to be 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 was when the mental health services suddenly realised there was a problem and became involved. They complained bitterly that no-one asked their advice, asked what they knew about their parent's illness, and what made it better or worse, when they had often been managing the situation for months without help. An example was a girl aged eight who had been both monitoring and managing her mother's medication, without any of the services being aware of it.

Inevitably, workers in mental health teams are the most likely to encounter children in the home, particularly in the acute phase, or when a child visits a parent on a ward. It is therefore necessary for each team to form a network with the local social services, CAHMS, and relevant voluntary bodies to develop a rapid response strategy for children who may be effected by a parent's mental illness. Each group needs to be assured that at least someone will be talking to the child, and to know who that person is. How to do it and what to say are outside the scope of this article. However, an ideal way to proceed is by setting up a local interagency group who may first need to discuss the kind of explanations they use, and then practise – possibly in role plays – engaging young children in these explanations.

The training pack attached to the film 'Being Seen and Heard' contains useful general advice about how to do this, as well as a manual – for those who find more prescriptive literature useful – about how to talk to children in such a situation.

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