

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

“You are unsure of who to trust. You don’t know who is telling the truth. You love your mum and want to believe her, even though what she is saying sounds a bit weird. But if you don’t believe your mother you feel guilty and you feel like you are deceiving her.”

– A young woman who from the age of nine cared for her two younger sisters and her mother, who has schizophrenia.



This is an edited version of a paper presented during the Institute's Fifth Australian Family Research Conference in Brisbane, in November 1996.

Meeting the support needs of families with dependent children where the parent has a mental illness



In April 1993 a research project titled Children of Parents Experiencing Major Mental Illness was initiated at the Early Psychosis Research Centre, The University of Melbourne, with the focus on children of parents experiencing psychotic disorders. It was the first attempt in Australia to address this question. Because there was no clearly identified group on which to focus, part of the process of the research was making the ‘invisible’ visible, and developing a culture in relation to children of parents with mental illness, and the role of parent in the lives of people traditionally identified simply as the patient, or client.

The questions addressed were: What did parents and professionals identify as the needs of the children? What did parents identify as their own support needs,

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and why did they not seek support? This issue is one which has always required attention on the grounds of basic human rights – the rights of children to grow up in the best possible environment, and the rights of parents to have the support required to provide this environment (United Nations Convention on the Rights of the Child, Article 18.2).

In previous eras the mentally ill were set apart and conferred with an inferior status. From this approach it followed that the specific and intimate issues of sexuality, fertility, pregnancy and childbirth in this population have been ignored. Pregnant women who were institutionalised were transferred to another hospital until the birth of the baby, then returned to the psychiatric institution alone; adoption

arrangements were made for the child by the maternity unit, when no family member was available to provide care (Apfel and Handel 1993).

More recently, the shift from care in an institution to care in the community, together with changed approaches in treatment and medication, means that people with mental illness are able to express their normal desires to form relationships and have children. The birth rate in this population consequently increased, and the community has been confronted with the need to respond simply because there are now more children (David and Morgall 1990).

Identifying Children and Parents

Data concerning the incidence of adult psychiatric patients who also have dependent children is not routinely collected, leaving estimates to be made from census and epidemiological data. In Australia it can be roughly estimated that there are 27,000 children affected. This is based on the number of women aged 20–45, the incidence and age of onset of schizophrenia and emotional disorders, and data on the proportion of women with such disorders who have children (Gottesman 1991).

This lack of data is not unique to Australia. Studies from the United States (Blanch, Nicholson and Purcell 1994), the United Kingdom (Poole 1996), and Denmark (Wang and Goldschmidt 1994) report that no statistics are available to indicate what proportion of patients with psychiatric illnesses are parents.

Risks for Children

Children of parents with psychotic disorders are at increased risk of developing such a disorder on genetic grounds (Ritsner, Karas and Drigalenko 1991); they are also at increased risk of developing emotional and behavioural problems on the basis of deleterious developmental experiences (Goodman 1984). This is more of an issue than in the past when it was routine to take children into care thus removing them from the negative effects associated with their parent's illness.

The emotional/behavioural problems for children do not stem, in the main, from the parent's mental illness, but rather from associated psychosocial disturbance in the family (Rutter and Qinton 1984). The risks of psychological, social and educational problems arise from poverty, family discord and disorganisation (including housing problems), and disruption in schooling and care due to repeated admissions of the parent to hospital (Silverman 1989).

Some children are resilient to poor outcomes. Factors contributing to resilience include the child's temperament, the availability of one or more adults with whom the child can develop a supportive relationship, the child's age at the time of parental breakdown, a stable, cohesive

family, and the extent and quality of the external support system (Garnezy, Masten and Tellegen 1984; Feldman, Stiffman and Jung 1987).

Different effects on children will be apparent at different stages of their lives. Babies may be less responsive and spontaneous, more withdrawn and apathetic. Primary school children may have low self-esteem, be anxious and withdrawn. Adolescents, in becoming increasingly aware of how different home and family life is, may experience low self-confidence, isolation, and feelings of responsibility (Goldstein 1987).

Identifying the Needs of Children and Parents

The aim of the research project was to identify needs of both children and their parents. Inclusion criteria for each data gathering step were: that parents had a diagnosed psychotic disorder; that they had one or more children under 18; and that they had full-time custody of their children, or had regular contact.

Parent survey

Parents made a direct and valuable contribution to the research. In 1994 and 1995 a total of 70 parents responded to a mail-out questionnaire, or participated in eight focus groups. Both procedures addressed the issue of service and



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support needs identified by parents for themselves and their children.

As parents with a psychiatric illness and their children may be clients of one or more government and non-government health and welfare agencies, a mailing list of 427 of these agencies, in Victoria, was prepared. Each agency received several copies of the questionnaire and explanatory letter requesting they distribute the questionnaire to parents. Parents were informed about the research project by a staff member and could take away the questionnaire with accompanying Plain English and Informed Consent statements for completion.

The focus groups were arranged with the cooperation of service providers interested in contributing to the research. Practitioners in eight community mental health or psychosocial rehabilitation settings approached parents whom they believed could contribute, and arranged the interview room for the agreed date.

Numbers in the focus groups ranged from two to four parents.

Table 1 and Table 2 summarise the questionnaire and focus group responses of parents concerning their own support needs and those of their children.

Table 1. Children's needs identified by their parents

Continuity of care and least disruption to home and school when parents are hospitalised
Explanation of events surrounding their parent's illness
Someone available for the child to learn to trust and talk to about fears, guilt, confusion
Programs where children can meet with other children

Table 2. Parent's needs identified by parents

Continuity of relationship with supportive worker
Reassurance about quality of their parenting
Quality care for their children
Suitable place for children to visit parents in hospital
Parent support groups
Understanding of mental illness in the community, including their own families

Parents were also asked about factors discouraging them from seeking help and support. Their greatest fear is that by asking for help, they will be seen as not coping and their children will be removed by child protection authorities. There is also the prevailing view that asking for help seems like failure, when it is important to feel independent and in control.

Service provider survey

In 1994 a brief survey of service providers was also conducted. The survey was mailed to over 600 health, welfare, government and non-government agencies in Victoria; 136 individual responses were received.

Service providers were first asked to identify the areas of greatest difficulty for children and the most effective interventions, and could make multiple choice responses to these questions. Eighty per cent of service providers considered that 'parenting' their parent was a difficulty for children. This may include reassuring their parent, defusing emotions, managing household chores and providing physical care. Seventy-six per cent of service providers also believed that a child's lack of knowledge and understanding about their parent's mental illness is a difficulty. Other identified areas of difficulty were the concern children have about future mental illness themselves, and isolation from other children.

The interventions identified by the majority of service providers as most

effective for children included support for parents, support for children at the time a parent is hospitalised, peer support groups and counselling for children.

A third, open-ended question asked service providers to identify their own needs in relation to professional development and skills training. Service providers identified the need for information and increased understanding about mental illness, particularly in relation to the implications for child protection. They would like to know how to talk sensitively with children about their parent's mental illness, as there is concern they could unnecessarily alarm or upset a child. They were also of the view that training would enable them to work more effectively with parents who do not identify or respond to their child's developmental needs. Resources which could help professionals work with families included workbooks and videos.



Parent interviews

Interviews with 13 parents were conducted in 1995. Some parents had participated in the earlier survey or focus groups, others rang to ask if they could participate. The purpose of the interviews was to document the degree and type of disruption occurring for families due to a parent's mental illness, and to understand how that may affect children.

Eleven mothers and two fathers were interviewed, with a total of 16 children; 11 of the children were aged between three and ten years, ten were boys, and most children lived with the interview parent.

Nine families involving 11 of the 16 children had experienced either the disruption associated with relationship breakdown or the involvement of child protection authorities. The degree of disruption is such that only two children, in two families, live with both birth parents. For three families conflict associated with marriage breakdown had seen Family Court intervention result in loss of custody and limits on access visits between parent and child. In each of these three families the parent had experienced the first episode of psychosis and hospital admission when the family was well established.

Seven parents had experienced their first episode of psychosis before becoming a parent, and have experienced far more hospital admissions than the other parents. One parent has been admitted 'countless' times, and one parent more than 20 times. For both of these parents the severity of their illness and lack of family support meant their respective children were placed in long-term alternative care as very young children. In one case the parent has regular though infrequent access visits with her child. In the other case parent and child were slowly reunited after the child had been in care for ten years, during which time the parent maintained consistent contact, despite having to travel long distances on many occasions.

During the interview, parents were asked if they were willing to complete a behaviour checklist for their child – the Parent Rating Scale of the Behavioural Assessment System for Children (Reynolds and Kamphaus 1992). Nine parents provided information about a total of ten children – eight boys and two girls aged between six and eleven.

Analysis of parents' responses showed that five of the children had two or more scores that could point to possible problem areas. The most noticeable areas were hyperactivity, aggression, and withdrawal. From what is understood from previous research it could be expected that some children may have behavioural or emotional difficulties. On the other hand, parent scores for three of the ten children were high on one or two of the adaptive or social scales, indicating the children's

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capacity to adapt to change, and their competence in the social skills area.

While no firm conclusions can be drawn from the assessments of these ten children, either individually, or as a group, it can be noted that where parent scores for children were satisfactory, those children had experienced least disturbance in family life. They were children of both two-parent and one-parent families, with a clearly distinguishing feature being the active involvement, in each case, of extended family.

The experience of one parent and her child illustrates the dilemma for a parent who needed help but was fearful of the possible consequences, and for her child who 'learnt fast'. The needs identified for parents and children reflect those described above.

The parent in question recognised that she was not well as she had grown up with her own mother who has schizophrenia. While recognising her own vulnerability, the parent did not want to seek help with her child as she was afraid he would be removed from her care. However, she subsequently acknowledged the need to ask for help, and her child, aged five, was placed in foster care where he remained for most of the next nine months.

From her experience this parent believes that education and appropriate planning around a parent's mental illness

would allow parents to arrange foster care placements for their children without feeling threatened that they will lose custody by doing so. This parent believes children need to know their parent's illness is not the child's fault; they also need to understand that their parent's mental illness affects behaviours and reactions. When this parent herself was a child no-one explained what the problems were for her own mother and, while wanting to comfort her mother at times, she was wary of being abused.

This mother also emphasised that children should not have to look after themselves. At the age of six, her son was taking care of her, and managing the daily routines himself, such as getting breakfast, and preparing for school – including making his own lunch. In the evenings he would encourage his mother to lie down while he prepared his dinner. This mother believes that children can feel totally responsible, and afraid that their parent will get sick again, and try and do everything they can to prevent that.

When the parent was discharged from hospital, and her son returned home, a safety network was established for him, comprising a list of names and telephone numbers of family and friends whom he could ring if he was worried. This contrasts with the experience of the young person quoted at the beginning of this paper who, as a child, with her siblings, felt very isolated and afraid, with no idea of where, and from whom, to seek support and protection.

Discussion

The information gathered from the surveys, focus groups and interviews does not provide neat answers about what should be done in practice to respond thoughtfully to such families, although there is clear recognition that needs of children and parents are not being met. While common issues and themes can be identified, each family is unique and does not fit a formula for service delivery.

For some parents and their children the effect of serious illness such as a psychotic disorder is isolation, loss of status and marginalisation. In families where this has not occurred it is encouraging to see that the extended family support available to them provides a buffer zone to protect the children and enables the parenting role to be shared with the parents. Some families are unable to benefit from family support for various reasons such as problematic relationships or the inability of the extended family to help.

Through each of the research stages, parents have highlighted that they are individuals with needs specific to each family and to each stage of parenting. We need to recognise that they are parents of children who depend on them, and for whom they want the best opportunities for growing up; that they are people who

also have an illness which may fluctuate, or may be chronic.

However, the problems posed in attempting to support effectively the parents and their children are too complex, and the solutions too comprehensive, for any one agency or organisation to address alone. Inter-agency partnership and collaboration with parents and among services is one effective way to ensure that all children and parents can feel that they are fully members of their community.

Recommendations

In thinking about a blueprint for identifying and responding to the needs of children and their parents there are three possible domains.

Most immediate and obvious is provision of programs for children and parents, such as peer support programs, counsellors skilled in helping children express their feelings about their parent's illness, and parent support programs for parents.

Second, the skilling and resourcing of professionals needs to occur so that they feel more confident in working with parents with mental illness, feel secure in speaking with children about this issue, and understand the possible impact on children of a parent's illness.

Third, the development of inter-agency cooperation and collaboration needs to be facilitated, to ensure that the needs of vulnerable children are identified and that they receive a response which is both planned and flexible to the fluctuations of their parent's mental illness. The needs of such families relate to a number of sectors – adult psychiatry, child psychiatry, family welfare, education and child protection, to name the most immediate. Others would be services which support non-English-speaking families, maternal and child health nurses, and community police.

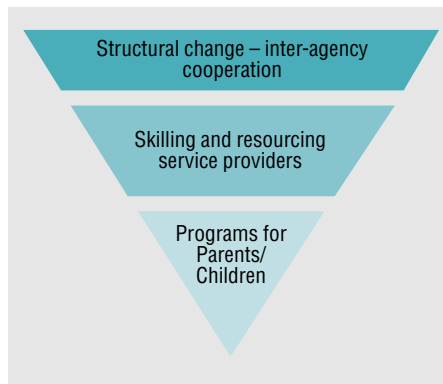
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Programs in Victoria

In Victoria at present there are developments in each of the three domains shown in Figure 1. In the southern region of Melbourne an inter-agency collaboration project, *Listen to the Children*, the Southern Partnership Project, is being implemented. Its aim is to bring together the agencies identified above to establish local networks that can then work towards a family management approach with a view to early intervention with children.

The Victorian Government has acknowledged the important role of mental health workers in the public sector, and has recently allocated funds for training programs which will sensitise workers to the issues for a client's dependent child-

Figure 1. Families with dependent children where parents have a mental illness: response domains



and to the needs of that client as a parent.

A peer support program for children of parents with mental illness has recently been piloted with funding from the National Mental Health Project (Commonwealth Department Human Services and Health 1994). (Pilot projects for children in other states have been funded from the same source.) Ongoing



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provision of any similar programs are dependent on new funding. Support programs for parents have been established where there are professionals with a particular interest in and understanding of the needs of the parents. Such programs provide parents with a supportive and safe environment in which to discuss personal and parenting issues.

Conclusion

The cultural shift required is now underway, with clear recognition that the parenting needs of people with mental illness, and the needs of their dependent children require a systematic response. Parents, adult offspring and children are actively contributing to this process by courageously speaking to the media, and also describing their experiences to tertiary students in social work, psychiatry

and other disciplines. In doing so they are both coming to terms with their own, sometimes traumatic, experiences and challenging community attitudes towards people with mental illness and their families.

References

- Apfel, R.J. & Handel, M.H. (1993), *Madness and Loss of Motherhood*, American Psychiatric Press, Washington.
- Blanch, A., Nicholson, J. & Purcell, J. (1994), 'Parents with severe mental illness and their children: the need for human services integration', *Journal of Mental Health Administration*, vol.21, pp.388–396.
- Commonwealth Department Human Services and Health (1994), *National Mental Health Project Funding Innovative Grants Program*, AGPS, Canberra.
- David, H.P. & Morgall, J.M. (1990), 'Family planning for the mentally disordered and retarded', *The Journal of Nervous and Mental Disease*, vol.178, pp.385–391.
- Feldman, R.A., Stiffman, A.R. & Jung, K. G. (1987), *Children at Risk: In the Web of Parental Mental Illness*, Rutgers, New Brunswick.
- Garmez, N., Masten, A.S. & Tellegen, A. (1984), 'The study of stress and competence in children: a building block for developmental psychopathology', *Child Development*, vol.55, pp.97–111.
- Goldstein, M. (1987), 'Psychosocial issues', *Schizophrenia Bulletin*, vol.13, pp.157–171.
- Goodman, S. (1984), 'Children of disturbed parents: the interface between research and intervention', *American Journal of Community Psychology*, vol.12, pp.663–687.
- Gottesman, I.I. (1991), *Schizophrenia Genesis*, Freeman, New York.
- Poole, R. (1996), 'General adult psychiatrists and their patients' children', in M. Gopfert, J. Webster & M.V. Seeman (eds) *Parental Psychiatric Disorder: Distressed Parents and their Families*, Cambridge University Press, Cambridge.
- Reynolds, C.R. & Kamphaus, R.W. (1992), *Behaviour Assessment System for Children*, American Guidance Service, Circle Pines.
- Ritsner, J.E., Karas, S.I. & Drigalenko E.I. (1991), 'Genetic epidemiological study of schizophrenia: two modes of sampling', *Genetic Epidemiology*, vol.8, pp.47–53.
- Rutter, M. & Quinton, D. (1984), 'Parental psychiatric disorder: effects on children', *Psychological Medicine*, vol.14, pp.853–880.
- Silverman, M.M. (1989), 'Children of psychiatrically ill parents: a prevention perspective', *Hospital and Community Psychiatry*, vol.40, pp.1257–1265.
- United Nations (1991), *Convention on the Rights of the Child*, United Nations, New York.
- Wang, A.R. & Goldschmidt, V.V. (1994), 'Interviews of psychiatric inpatients about their family situation and young children', *Acta Psychiatrica Scandinavica*, vol.90, pp.459–465.

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