

CHAPTER 11

FAMILIES AND CARERS

Introduction

11.1 Families and carers are usually at the centre of community mental health care, providing the bulk of support and assistance, often with little, if any, specialised training or expertise in the area.¹ The National Mental Health Plan 2003-2008 emphasised the importance of involving carers, in addition to consumers, in all levels of policy, planning and treatment. It acknowledged the central role of carers, many of whom are family members, in the provision of mental healthcare.²

11.2 Carers assist people with mental illness, providing housing, personal care, and employment and employment assistance. They often assist in delivery of treatment, make clinical appointments, follow up on treatment and prescriptions, and provide transport. Most of all, carers can provide social networks, love and the positive attitude that is known to assist in recovery.

11.3 Carers are people, but being a carer is a role, not the whole person. The role of a carer may be performed by a family member, partner, friend or neighbour, or may be someone previously unknown to the consumer, such as a worker from a not-for-profit organisation or someone hired to provide a level of service.³ Regardless of who actually fills the role, it is important to recognise that carers are individuals with their own life and needs.⁴

11.4 Carers said they often lost their sense of self, due to the intensive and demanding nature of the task. Carers may perceive themselves only in the context of being a 'carer', particularly when the carer is also a family member.

11.5 Family members of people with mental illness need adequate opportunities to perform other roles and to promote and maintain a nurturing family environment. They need opportunities to maintain their relationships as wives, husbands, partners, mothers, fathers or siblings, not only as carers. For children who have a parent or parents with mental illness, their ability to just 'be a child' with the room to grow and learn, and have the freedom to explore opportunities available to other children who do not share the same level of additional responsibility can be severely restricted.

1 Name withheld, *Submission 63*, p. 1.

2 Australian Health Ministers, *National Mental Health Plan 2003-2008*, p. 10.

3 National Network of Private Psychiatric Sector Consumers and Their Carers, *Submission 189*, p. 10.

4 Diane Williams, *Submission 184*, p. 2.

11.6 This chapter reviews family and carer support needs in several areas - education and training; financial support; the special needs of children; and parenting, relationships and family functioning. The chapter then discusses mental health issues related to some particularly complex and difficult family situations.

11.7 In addition to the topics covered in this chapter, the committee acknowledges the importance of access to adequate employment and accommodation in the process of providing care to people with mental illness, as well as the need for respite care to alleviate the burden on carers. These topics are discussed in other chapters - Chapter 10, Non-health support services and Chapter 9, Care in the community.

Supporting the roles of families and carers

11.8 The benefits of having family members involved in care are clear:

It is generally recognised that the prognosis for people with mental illness, who have family carers, is better than those without such support.⁵

11.9 Families as carers are often extremely devoted and committed to the recovery of the person they are caring for. That commitment is often an advantage in ensuring quality care as well as advocacy on behalf of the consumer. Carers often live with consumers, meaning there is a continuity of care that can be hard to otherwise achieve. And as many submitters pointed out, the care of family members saves governments a great deal of money.

11.10 However, families can become stretched delivering long-term care with limited support.⁶ This can be distressing for carers, especially when there are several family members affected by mental illness. One carer, supporting both his wife and son said:

This system allows carers to become so overburdened caring for their loved ones (that) the carers become depressed and sick. In my current situation, I see no bright future for us to be together...⁷

11.11 It is also important that administrators of psychiatric facilities are sensitive to the role and needs of families in the lives of consumers.⁸

11.12 Carers described the continuing challenges they face obtaining service and support:

The father described to me how he has to go to the community centre and “have a fit” to get any real attention for his son... I suggested that the father

5 Name withheld, *Submission 62*, p. 1.

6 The Association for Australian Rural Nurses, the Australian and New Zealand College of Mental Health Nurses and the Royal College of Nursing Australia, *Submission 321*, pp. 12–13.

7 Name withheld, *Submission 132*, p. 3.

8 Confidential, *Submission 489*, p. 2.

needs regular session about once a month to get support. This will be considered a novel and perhaps unnecessary process I suspect. The son is actively psychotic and treatment resistant. There is NO respite or support for the father. He was lucky to find a bulk-billing (for pensioners) psychiatrist. It is little wonder many families consider murder suicide.⁹

11.13 In order to effectively fulfil their roles, families and carers need adequate support in a range of areas:

- Comprehensive and accessible information about acute care and community-based mental health services, as well as information about the relevant mental illness and treatments;
- Respite for carers;
- Access to emergency funding in a time of crisis;
- Mediation support;
- Individual counselling options;
- Family counselling and support for siblings; and
- Early intervention programmes for young people with emerging psychosis.¹⁰

Families' and carers' need for information

11.14 Carers submitted that they were not usually provided with any information, much less comprehensive information, about the condition of the person for whom they were caring. They were not typically involved in care planning and needed greater access to specialist medical health care providers in the event of hospitalisation:

... the role of the carer in service delivery is often ignored, rejected or seriously undervalued ... The carer's rights are not observed nearly so assiduously. This has particular significance when the consumers are young people who are still the financial and psychological responsibility of their parents.¹¹

When our system chooses to devalue, ignore and disregard the valuable, intimate knowledge and understanding one family member has of another family member, there is a large price to pay for all concerned.¹²

11.15 However, the views of some consumers indicated a tension between the interests of carers and consumers:

9 Associate Professor Brian Boettcher, *Submission 1*, p. 12.

10 Anglicare Tasmania, *Submission 464*, p. 17.

11 National Network of Private Psychiatric Sector Consumers and Their Carers, *Submission 189*, p. 10.

12 Ms Sharon Ponder, *Submission 84*, p. 9.

Many consumers like their carers to be involved, however, [also] want to reserve the right to not have their carers involved in every aspect of their treatment and recovery. [H]owever carers and mental health service providers tend to totally step on such boundary issues and ignore the consumer's wishes of when s/he would like to have their carer involved and when s/he would prefer not to.¹³

11.16 Carers explained that the usual reason they were given for not being provided with information was that to do so would be contrary to the provisions of privacy legislation. However, one witness submitted that the Victorian Mental Health Act, for instance, exempts providers from the need to keep information about patients confidential from guardians, family members or primary carers if:

the information is reasonably required for the on-going care of the person to whom it relates; and

the guardian, family member or primary carer will be involved in providing that care.¹⁴

11.17 The witness stated that:

Clinicians routinely flout the Mental Health Act by ignoring this provision of the Mental Health Act and denying essential information to carers, often, as in my son's case, with deadly results.¹⁵

11.18 There was a call for clearer guidance in this area:

National standards that make explicit the methods that can be used to involve carers would be [of] value in addressing outmoded paradigms of family involvement that many clinicians still have.¹⁶

11.19 The rights of consumers and carers are discussed in more detail in Chapter 3 – The rights of the mentally ill.

Education and training for families and carers

11.20 Living with and supporting family members with mental illness is challenging. Hundreds of carers and family members wrote to the committee sharing their experiences, frustrations and disillusionment with services. One carer commented:

I now understand why many families let their mentally ill children go – the situations seems impossible and the person with mental illness often does not respond, does not learn, does not show up, changes his or her mind

13 The Northern Beaches Mental Health Consumer Network, *Submission 60*, p. 14.

14 Mr Graeme Bond, *Submission 484*, pp 4–5.

15 Mr Graeme Bond, *Submission 484*, p. 5.

16 Mental Illness Fellowship of Australia Inc, *Submission 402*, p. 5.

about nearly everything almost daily, and is adept at lying, stealing – whatever it takes.

Despite the seeming hopelessness of my daughter's situation, however, I kept in touch...¹⁷

11.21 There is a definite need for specialised programs to assist carers and families:¹⁸

The majority of funding for carer training and support is only available through generic carer support programs where the NMHS does not have a role. The generalist programs have little ability to focus on the specific needs on mental health carers, even if they had the funds to do so. Some of the identified differences are the stigma of mental illness, the course and onset of the illness, financial impacts, dual diagnosis and the rejection of the carer.¹⁹

11.22 The Mental Illness Fellowship of Australia (MIFA) observed that carers who are educated, trained, informed and supported cope better, and are able in turn to provide better support. This contributes to the long term well-being and rehabilitation of their loved ones, including improving medication compliance and reducing relapse.²⁰

11.23 Information and training for carers and families is needed from the initial diagnosis of mental illness. It must be accurate and specific to the individual care and treatment needs of the person they are supporting.²¹ Training should be provided in terms that are understandable to non-healthcare workers:

It is hard enough realising a family member has a mental illness without having to learn the “language” to use when speaking to the service providers and health professionals.²²

11.24 Training and support for families and carers needs to be cognisant of, and certainly not detrimental to, the independence of consumers:

[Training] needs to inform and empower family members, building positive, but realistic attitudes and developing interpersonal and problem-solving skills. In the past there has been too much emphasis on the "plight"

17 Name withheld, *Submission 375*, pp 8–9.

18 See for example, Name withheld, *Submission 53*, p. 1; Mill Park Family Support Group, *Submission 72*, p. 3; Name Withheld, *Submission 75*, p. 2; National Network of Private Psychiatric Sector Consumers and Their Carers, *Submission 189*, p. 10. Consumers and Carers from the NSW Far South Coast, *Submission 5*, p. 2; Brian Haisman, *Submission 114*, p. 2; Mental Illness Fellowship of Australia Inc, *Submission 402*, p. 5.

19 MHCA, *Submission 262*, p. 30.

20 Mental Illness Fellowship of Australia Inc, *Submission 402*, p. 5.

21 The Northern beaches Mental Health Consumer Network, *Submission 60*, p. 14;

22 Mill Park Family Support Group, *Submission 72*, p. 3.

of carers, their "self-sacrifice", their "heroism", etc. This has been unhelpful, counterproductive and isolating from the mainstream community. Training also needs to engender respect for the person who is ill. It needs to include strategies for lifting his/her self-esteem and strategies for attaining as much independence as possible for the person who is ill as well as aiming at including him/her in mainstream community life.²³

11.25 Carers noted that without information they did not know if their endeavours were providing the best support for the consumer:

We appreciated that the best form of treatment was ours, as it was constant, readily available and there 24/7. However, the frustrating lack of information and support services for families and carers of those with depression left us ill equipped to provide the help and support dad needed. We worry now that perhaps what was well intended may in fact (have) been negative and adverse to helping him with his battle with the illness.²⁴

11.26 As with other aspects of mental health service provision, the voices and experiences of consumers are instrumental in educating families and must be central to training programs. Carers and consumers endorsed support groups where experiences can be shared:

Some of the most effective support and advice for people suffering from mental illness and their families is provided by people who share the same problems. There is a need to strengthen and expand the role of so-called "consumer consultants" and make their work in the community a reality.²⁵

11.27 Submissions also emphasised the importance of recovery focussed training and support. For carers, who can be overburdened, there is a need for support which enables them to believe in recovery:

Carers need to be well resourced and services to assist them to rekindle their own hope in the people they are caring for. Vital to this are the support groups which help provide links between carers and which are the best equipped to resource and train carers. These mutual self help groups are not receiving sufficient funding to adequately deliver these support services and to organise training for carers.²⁶

11.28 Many families will be performing their role as carers for the duration of either their own life or throughout the lifetime of the person with the mental illness, so education, training and support is needed on an ongoing basis.²⁷ However, intensive, short-term support to families and carers is also required. For example, Anglicare

23 Ms Sheelah Egan, *Submission 113*, p. [7].

24 Name withheld, *Submission 9*, p. 1.

25 Name withheld, *Submission 375*, p. 3.

26 VICSERV (Psychiatric Disability Services of Victoria), *Submission 347*, p. 21.

27 Name withheld, *Submission 38*, p. 2.

commented on the lack of referral services upon discharge from hospital, particularly after a first admission:

The length of this waiting list for essential treatment, rehabilitation and support services at a time when individuals and their family are in a state of crisis, confusion, fear and grief is inappropriate and potentially tragic.²⁸

11.29 The stress on families related to the lack of discharge planning and community based services to support the transition back into community life is also discussed in Chapter 9.

11.30 Easily accessible information about the services available in the mental health sector is lacking. This can create barriers to seeking care and treatment beyond what may be provided by a family member:

It was not until in desperation and in urgent need of respite from my home situation that I attended a carer support group where I learned how to describe what was happening for my son; and also how much more support my son needed (than I was able to give), and how the mental health system is structured to meet this need.²⁹

Training and support programs

11.31 Non-government organisations are providing valuable programs to assist and support carers in the community, but the lack of resources restricts what is achievable. This is particularly so for community organisations reliant on volunteers, many of whom are themselves the primary carers for a family member with mental illness.³⁰ Despite these constraints, there are several organisations that provide valuable peer support and training for carers.

11.32 The Association for Relatives And Friends of the Mentally Ill (ARAFMI) is a non-profit organisation, providing mutual support and understanding for people with a mental illness, their families, friends and carers. ARAFMI delivers a range of services, including counselling, information and support, through its numerous branches spread across the states and territories. ARAFMI has a number of initiatives specifically targeting the practical and responsive needs of carers, as well as programs addressing the needs of young people.³¹

11.33 The Mental Illness Fellowship of Australia (MIFA) supports the needs of consumers, their families and friends through a range of education, support and advocacy services. Fellowships exist at state and territory level, and provide a range of community-based services, which include: support and self help programs to enhance

28 Anglicare Tasmania, *Submission 464*, p. 16.

29 Name withheld, *Submission 100*, p. 2.

30 Canberra Schizophrenia Fellowship, *Submission 103*, p. 6.

31 DepressionNet, Association for the Relatives and Friends of the Mentally Ill (ARAFMI), <http://www.depressionet.com.au/famfr/arafmi.html>, (accessed March 2006).

the skills of consumers and assist in rehabilitation and recovery; outreach and accommodation services; and, respite and residential rehabilitation services. MIFA stated that the shortage of state and federal funding severely limits its ability to deliver much-needed services to the community.³²

11.34 Drawing on findings from the NSW parliamentary inquiry into state-wide mental health services, the Mental Health Coordinating Council (MHCC) noted the number of 'family- and carer-friendly' services within the state that seek to increase the involvement of primary carers in treatment, care and recovery, as well as providing education, information and respite to assist carers. Initiatives included:

- Carers NSW has developed a "Carer Life Course Framework: An Evidence Based Approach to Effective Carer Education and Support".
- The Association for Relatives And Friends of the Mentally Ill (ARAFMI) is nearing completion of the Carer Services Mapping Project, providing recommendations for improving services, training, education, information, advocacy, planning and support for carers. The project will lead to the establishment of a carer services information database.
- Establishment of the Carers Support Unit, which is the largest service provider to carers of people with mental illness in the state.
- Development of a "Framework for Family and Carer Support in Mental Health Services."
- Agreement to allocate funds to the Working with Families Project, which is a framework for family and carer support.³³

11.35 However, MHCC also raised concerns about the inadequacies of, and uncertain future access to, funding for many of these programs.³⁴ Such concerns occur across jurisdictions. For example, in Victoria the Mildura Mental Health Service has established a Carer Consultant. The position delivers a range of services, including: support to carers; conducting carer surveys; providing input to planning meetings and carer forums; and, implementing policies and strategies for improving carer services. Whilst the value of carer-specific services was recognised in the Victorian Government's 'Caring Together' action plan, the Mildura Health Service voiced concern about the lack of funding to deliver a comprehensive service (the position is currently funded for only two days per week) and the absence of a consistent funding stream to provide a continuum of service.³⁵

11.36 The Mental Illness Fellowship of Australia (MIFA) has tried a program for carers ('Well ways – a traveller's guide to wellbeing for families of people with mental

32 MIFA, *Submission 402*, p. 2.

33 Mental Health Coordinating Council, *Submission 172*, p. 10.

34 *Submission 172*, p. 6.

35 Mildura Mental Health Services, *Submission 96*, pp 1–2.

illness') developed by the Mental Illness Fellowship of Victoria. The program is designed to 'increase the capacity of families, carers and friends to care effectively for themselves, other family members and their relative living with mental illness'.³⁶ It includes training in the cause, treatment and recovery from mental illness, the experience of families and the legal, health and carers support system. The program is designed to include a monthly support group for up to 18 months, to reinforce learning, provide feedback and support behavioural change. Evaluation of the program found that:

...caregivers were less anxious and depressed and reported less worry regarding the person with a mental illness following participation in this program.³⁷

11.37 However, due to a lack of funding, efforts to roll the program out across all states and territories had limited success:

Despite the evidence, funding for specific programs in most jurisdictions within Australia is poor or at worst non-existent. The non-government sector of mental health is struggling to survive in many locations throughout Australia. This fact has been borne out during the current project with a number of MIFA members unable to proceed with implementing Well Ways within their state or territory.³⁸

11.38 Concerns about funding and development of programs and supports for families and carers were echoed across the community:

Various Australian standards, policies and guidelines do in fact recognise a real role for carers, but this seems to be largely ignored in practice, despite system rhetoric to the contrary. Implementation lags significantly.³⁹

Financial support

11.39 Mental illness can have serious financial consequences, both for the consumer and for those who provide care and support:

Carers too can find themselves caught in a spiral of social-economic disadvantage if they lose the financial support of family, their family homes or their savings as a repercussion of the care they provide.⁴⁰

36 Mental Illness Fellowship of Australia Inc, *Submission 402*, Attachment 1, Farnan, S., Crowther, L. and Springgay, M. 2004, 'Well Ways – a traveller's guide to wellbeing for families of people with mental illness, A multi-family peer psycho-educational program', p. 3.

37 Mental Illness Fellowship of Australia Inc, *Submission 402*, Attachment 1, Farnan, S., Crowther, L. and Springgay, M. 2004, 'Well Ways – a traveller's guide to wellbeing for families of people with mental illness, A multi-family peer psycho-educational program', p. 15.

38 Mental Illness Fellowship of Australia Inc, *Submission 402*, Attachment 1, Farnan, S., Crowther, L. and Springgay, M. 2004, 'Well Ways – a traveller's guide to wellbeing for families of people with mental illness, A multi-family peer psycho-educational program', p. 16.

39 Mr Brain Haisman, *Submission 114*, p. 2.

11.40 Family members performing the role of carers are often forced to give up full-time employment, significantly reducing family income. Given the additional expenses incurred in caring for a family member with mental illness, inadequate community support and little financial assistance mean many families cannot cope:

They are more often than not forced to leave their jobs in order to cope with their family member and the illness. They rarely receive a carer's pension and, even if they do, it certainly does not replace the income they were previously earning. A lot of families disintegrate due to the strain of learning to cope with mental illness and still trying to hold a family unit together.⁴¹

11.41 While little research has been done on the specific pattern of expense for carers of people with mental illness,⁴² the kinds of financial assistance provided include: fees for accessing healthcare professionals not covered under Medicare; travel costs for getting to and from healthcare appointments; replacing items destroyed or lost by loved ones during episodes of psychosis or dysfunction, including clothing, repairs and replacement furniture and lost rental bonds; payment of fines and debts accumulated by the mentally ill family member including court fines, parking fines, credit card debts, hire purchase debts and telephone debts.⁴³

11.42 The impact of providing financial support is compounded when the person with a mental illness is geographically isolated and the carer must travel long distances to access support services both for the consumer and for themselves as the carer.⁴⁴

11.43 Anglicare summarised that '(t)he impact of these costs on parents who were themselves on low incomes was significant', and that '(g)iven the many benefits which flow from family support, it is a major concern that so few carers of people with mental illness receive financial support for their role'.⁴⁵

11.44 The committee heard that it is common for families to be unaware of the carer payment available through Centrelink.⁴⁶ However, the difficulties in obtaining a carer's allowance were also reported:

40 Anglicare Tasmania, *Submission 464*, p. 31.

41 Mill Park Family Support Group, *Submission 72*, p. 3.

42 Anglicare Tasmania, *Submission 464*, p. 31.

43 Mental Carers Network Inc, *Submission 286*, p. 4; Anglicare Tasmania, *Submission 464*, p. 31–32.

44 National Network of Private Psychiatric Sector Consumers and Their Carers, *Submission 189*, p. 10.

45 Anglicare Tasmania, *Submission 464*, p. 32.

46 Mental Health Community Coalition of the ACT Consumer and Carer Caucus, *Submission 214*, p. 7.

A carer of someone that requires physical feeding, washing etc is considered the norm but the carer of a mentally ill person who doesn't want to get out of bed to wash, doesn't care what they eat etc is not even acknowledged. It can be equally draining and stressful with similar outcomes but one carer is allowed the benefit the other not.⁴⁷

11.45 Carers also commented on the low level of financial support provided:

I have had to leave my position as a senior social worker RGH(H) after 20 years working in ICU/CCU hospital settings. I receive a carers' allowance of a laughable \$45 odd dollars a week. I receive no other assistance, benefits or relief from my most important role as a full-time carer.⁴⁸

11.46 Ageing parents of people with mental illness expressed particular concern about the lack of financial assistance, now and for the future.⁴⁹ The National Rural Health Alliance stated the need for long-term planning to alleviate the distress faced by older parents who worry what the future may hold when they are no longer able to care for family members with mental illness.⁵⁰ As one mother wrote:

At present our son lives with us, his ageing parents (close to 80 years). Where will he go when we are not here or incapable of looking after him?⁵¹

The special needs of children

11.47 The experience of mental illness can be traumatic for family members, particularly for children and young people. Mental illness among parents can have a range of impacts on children, including:

- Children of parents with mental illness have a greater likelihood than other children of having emotional and behavioural problems;
- Children worry about their parents and are not given information by mental health professionals which would reduce their anxiety;
- Parents do not seek help and support due to fear of their children being taken from them by welfare authorities; and
- Parents and families are reluctant to talk with children about the mental illness of a family member. As a result children feel isolated not knowing that other children share their family experience.⁵²

47 Ms Paola Mason, *Submission 142*, p. 5.

48 Name withheld, *Submission 144*, p. 1.

49 See, for example: Name withheld, *Submission 61*, p.1; Name withheld, *Submission 144*, p. 2.

50 National Rural health Alliance Inc, *Submission 181*, p. 25.

51 Name withheld, *Submission 56*, p.1.

52 Ms Vicki Cowling and Dr Adrian Falkov, *Submission 386*, p. 4.

11.48 Ms Vicki Cowling and Dr Adrian Falkov noted that 'Schools are opportune settings for increasing community understanding, and changing attitudes towards people with mental illness'.⁵³ They also point to the need for child and family welfare sectors to work collaboratively with mental health services, and for service providers, particularly after hours crisis services, to be trained in dealing with children of people with mental illness, including explaining events, answering questions and reducing anxiety in the short-term.⁵⁴

Child 'carers'

11.49 One group of children particularly in need of specialised services and support are children whose parent or parents have a mental illness.

Some children also bear the burden of caring for an adult with mental illness. This is an especially difficult task given the social isolation often associated with mental illness and can in turn affect the mental health of the child. These needs cannot be met by increasing capacity within the general service sector. Young carers and young people in families affected by mental illness should be identified as a priority target within children and youth services.⁵⁵

11.50 The expectation that children can fill the role of carer on an ongoing basis can have a significant impact on a child's wellbeing and future opportunities:

These children are foregoing a normal childhood because in most cases they 'have' to be the carer as there is no one else available to be. They are given very little assistance with their education and mostly leave school early with a very limited and interrupted education. Many are unemployed as a consequence of limited education, poor employment skills and the time-consuming role of carer. They are ashamed of their situation and are often bullied and victimised by peers who have no understanding of their situation.⁵⁶

11.51 There is a distinct lack of support services designed specifically for children in these circumstances. Submissions noted that the support services currently provided to carers often do not meet the needs of these children. For example:

The respite care that may be given is quite often restricted by OH&S laws, thus limiting what workers can do and resulting in the children still being responsible for the heavy workload. At other times the respite care is inappropriate, such as a worker sitting on the lounge with the consumer while the child is washing the dishes or making beds.⁵⁷

53 Ms Vicki Cowling and Dr Adrian Falkov, *Submission 386*, p. 5.

54 *Submission 386*, pp 2–3.

55 MHCA, *Submission 262*, p. 20.

56 Ms Janine Anderson, *Submission 210*, p. 3.

57 *Submission 210*, p. 3.

11.52 Some of the particular needs of children whose parent or parents have a mental illness include:

- emotional and practical support;
- respect for their role as a carer;
- appropriate respite;
- support to maintain the family as a unit;
- advocacy services for their rights and needs;
- personal development;
- assistance to participate in education and social activities; and
- special training and education in their role as carer, particularly as programs developed for adult carers may not be meaningful for a young audience.⁵⁸

11.53 The Network of Carers for People with a Mental Illness recommended continued funding to programs targeting child and adolescent carers, such as Children of Parents with a Mental Illness and Paying Attention to Self, to ensure the needs of these young carers are met.⁵⁹

Relationships and family functioning

11.54 Many families and carers are desperate for assistance which would help them respond appropriately to the needs and behaviours of a family member with mental illness, and also would help them deal with their own feelings and reactions to the illness. The committee heard that some families feel unable to respond to members with mental illness, and that stigma and prejudice is evident in some families:

When people admit to having diabetes or depression ...there is sympathy and support at almost every turn. However, mention that you suffer from schizophrenia and people literally take a step backwards, often as if they expect you to start ranting and raving at them. Most members of the Group have faced constant isolation, even from their own family members. Some relatives feel that the illness might be contagious, so they simply stay away in the hope that they won't "catch it" as well.⁶⁰

.....

My son had been noticeably ill for at least 6 months before I considered taking him to a psychiatrist. Immediate family who now do not live with us were not in favour of this course of action, and I also hesitated as it would then label my son with a very difficult and unattractive condition.⁶¹

58 AICAFMHA, *Submission 83*; City of Port Phillip, *Submission 326*, p. 17; Health Coordinating Council, *Submission 172*.

59 The Network of Carers for People with a Mental Illness, *Submission 227*, pp. 1–2.

60 Mill Park Family Support Group, *Submission 72*, pp. 3–4.

61 Name withheld, *Submission 100*, p. 2.

.....

No patient is alone. He or she is a member of a family; the two cannot be separated. The patient's ill health affects the family; it frightens the family. The family's fears, worries, perhaps deprivation, will affect the mind and anxiety of the patient.⁶²

11.55 Even among families with the best intentions and knowledge, family dynamics and relationships can be uncondusive to good mental health outcomes for both consumers and carers:

With limited access to information and support, many families attempt to control the situation by either wrapping their loved one in cotton wool and doing everything for them, or using 'power over' tactics in an attempt to force conformity to their 'beliefs' about how 'their family' members 'should' or 'ought' to behave.

... A major barrier experienced by many families is the belief that they have bent over backwards to accommodate the needs of their child, parent or sibling to the point where they themselves are experiencing massive stress, anxiety and grief at not being able to 'fix' the 'problem'.⁶³

11.56 Consumers described the impact family relationships can have:

Many carers treat the family member who is a consumer as if they have suddenly lost their adult status as like other siblings and tend to "over protect" the consumer, treat the consumer as if still a child and operate more from feelings of guilt of having brought into this world a person who has developed a mental illness rather than a human being who is capable of anything s/he puts their minds to despite the fact of living with a disability.⁶⁴

11.57 Professor Jorm also commented on family behaviours, and that families' immediate or natural reactions are not necessarily conducive to mental health outcomes:

There are some basic things that we should all know. A lot of research shows that if people with mental disorders are criticised by those close to them, that tends to give them a worse outcome. Unfortunately, it is a very natural thing for all of us when we do not like the way people behave to try to change their behaviour by criticising them. We naturally fall into it, but it is a destructive thing to do and it is a self-defeating way to try to change people's behaviour. So a very simple message that everybody in the community should know is that criticism only makes it worse.⁶⁵

62 Mr Peter Hutten, *Submission 185*, p. 19.

63 Ms Sue Koningen, *Submission 538*, p. 7.

64 The Northern Beaches Mental Health Consumer Network, *Submission 60*, p. 14.

65 Professor Anthony Jorm, *Committee Hansard*, 1 February 2006, p. 57.

11.58 One mother described her experience coming to terms with her daughter's mental illness:

I have learned over time to draw more and more boundaries. As I have gotten better (with coping), I think I could say, I have learned to put more boundaries between me and my daughter...because I know that ultimately she is the one that must decide to take her medicine and so on. On the other hand, I also know that that means that people will die; I am sure of it, even her. I have had to face that fact and the fact that she needs her autonomy...⁶⁶

11.59 Ms Sue Koningen told the committee about her consumer-driven program which 'helps families learn to cope more effectively to support their consumer to learn to self-manage their illness and work toward their recovery'.⁶⁷ She outlined the need for families to 'look at their family system, expectations, beliefs, behaviours and communication style so that they can reflect on the impact this may be having on their relationships with the people they love and value most in their lives – the ones they are trying so desperately to save or change'.⁶⁸

11.60 Ms Koningen's program focuses on rebuilding healthy relationships, including building resilience, hope and a focus on recovery.⁶⁹ Given sensitivities around reviewing family dynamics, consumer and carer involvement is important:

There is massive guilt along with massive grief. So much is determined by the facilitator and how they approach it. I have a lot of laughter. ... So on the one side, yes, we need to understand which behaviours are destructive but on the other hand we are becoming so much more powerful because we have got a better life, we have got a better relationship with everybody. I do not mean just with the child but with siblings, peers, work, everything. ... It is approached very gently. I think it works because I am one of them. If somebody else was to do it, I do not think they would be able to get away with it, quite frankly.⁷⁰

Parenting

11.61 Recognising the important role that families play in promoting mental health, some parents may need assistance to fulfil parenting roles, particularly where a child has a behaviour disorder. Individually tailored strategies for parenting children with challenging behaviours can have enormous benefits for both the child and the parent:

66 Name withheld, *Committee Hansard (in camera)*, 3 August 2005, p. 10. Agreed for citation with the witness.

67 Ms Sue Koningen, *Submission 538*, p. 2.

68 *Submission 538*, p. 7.

69 *Submission 538*, pp 11–12.

70 Ms Sue Koningen, *Committee Hansard*, 2 February 2006, p. 59.

I learnt how to deal with a child who had learning disabilities and other problems. They taught me how to do that because you cannot as a parent know how to deal with a child who is uniquely difference (sic), like my son is, and you need to be taught how to discipline them. You do not discipline them like you do your other children. I did not know how to discipline this child. I did not know how to teach him.⁷¹

11.62 Programs which assist parents, such as the Triple P-Positive Parenting Program, can help provide early intervention and assist in prevention of mental illness. This program contributes to early intervention and prevention of mental illness through recognition that not all parents know how to best fulfil their role as a parent and may need some additional assistance to minimise behavioural difficulties in their children. The Triple P program, developed at the University of Queensland, delivers parenting skills through attendance at either face-to-face individual or group sessions, or through self-help course material.

11.63 The Triple P program is a form of behavioural family intervention, and there is strong empirical support for this approach to treating and preventing childhood disorders.⁷² The Queensland Government has stated its commitment to the program by training and accrediting child health nurses and allied professionals to assist in early detection and intervention of child behaviour problems.⁷³ However, the ADGP has called for a nation-wide roll out of programs, such as Triple P, to provide an 'investment in strengthening the role of families'.⁷⁴

11.64 It is also important to acknowledge the diverse range of family circumstances and childhood disorders that parents face. The Learning and Attentional Disorders Society of WA Inc (LADS) commented that generic behaviour management programs, such as Triple P, are of little benefit to parents of children with ADHD.⁷⁵ Specific, targeted programs may be needed for these parents.

Pressures on the family and the impact on mental health

11.65 Breakdown of families, stresses within families and absence of families, combined with a lack of adequate community-based services and support, can lead to families being less than effective and can create or exacerbate mental illness in family members.

71 Miss Katherine Frances, *Committee Hansard*, 1 September 2005, p. 64.

72 M. Sanders, Markie-Dadds, C. and Turner, M. "Theoretical, Scientific and Clinical Foundations of the Triple P-Positive Parenting Program: A Population Approach to the Promotion of Parenting Competence", *Parenting Research and Practice Monograph No. 1*, p. 3.

73 Queensland Government, *Submission 377*, p. 36.

74 Australian Divisions of General Practice, *Submission 308*, p. 5.

75 Learning and Attentional Disorders Society of WA Inc, *Submission 202*, p. 9.

11.66 The MHCA recognised the potential impact of family breakdown on mental illness:

The third great failing of the NMHS is that it did not adequately plan for the increase in demand which is such a significant feature of mental health care at the present time. ... proper allowance was not made for an increase in mental illness among young people; for increasing incidence of mental illness brought about by family breakdown, decreasing participation in community and recreational networks; and increased drug and alcohol abuse.⁷⁶

11.67 The committee heard about some particular family experiences and circumstances that create great stress and impact on mental health. These circumstances are discussed below.

Families at risk

11.68 Some families face multiple challenges and are at particular risk of psychological dysfunction. Family environments can be far from therapeutic.

The most difficult client base to work with is the family where mental health issues are complicated by drug and alcohol problems. These families are difficult to engage and workers are often in vulnerable situations where safety is a concern not only for family members but also the worker themselves.⁷⁷

11.69 The Australian College of Psychological Medicine called for more resources and intervention to support socially-disadvantaged parents:

Supportive intervention needs to occur much earlier to treat parental dysfunction, teach anger management, teach survival strategies that don't involve substances and self harm and above all, help parents manage their children in non-damaging ways.⁷⁸

11.70 Children of parents with mental illness are over represented in the child protection system,⁷⁹ partly reflecting the lack of early treatment and support for parents. Catholic Welfare commented on one of its programs aimed at diverting families from the statutory Child Protection System:

One of the most significant issues seen in this team is the number of parents presenting with symptoms deriving from complex, long term trauma for which they have received little assessment or treatment.⁸⁰

76 MHCA, *Submission 262*, p. 18.

77 City of Port Phillip, *Submission 326*, p. 18.

78 ACPM, *Submission 411*, p. 11.

79 Ms Vicki Cowling OAM and Dr Adrian Falkov, *Submission 386*, p. 4.

80 Catholic Welfare, *Submission 302*, p. 15.

11.71 Service providers commented on the need for better integration between services to meet the needs of families at risk, for example collaboration between mental health services and wider family services such as family mediation and family therapy:

Mental illness is one of the factors adding to the increasing complexity of family life, with a number of co-factors: including drug and alcohol use, intellectual disability, and family violence, it requires skilled, joined-up interventions to improve the outcomes for children and families.⁸¹

11.72 Some families need assistance with living skills and family functioning in order to create an environment conducive to mental health:

There is no service available to give ongoing practical domestic support and role modelling ... Further resourcing and training for Family Support Services would greatly benefit the number of support groups and short term specific support able to be offered in particular to families with children between the ages of 12 and 18 years where support and programs of any kind is inadequate.⁸²

11.73 The City of Port Phillip noted that Maternal and Child Health Services offers universal care and support to all families with children aged 0-6 years, giving access and insight into family circumstances at an often vulnerable stage in life. However the service is not resourced to provide the supports needed for families with mental health issues; there are limited counselling and support groups and long referral waiting times.⁸³ With better resourced community-based mental health services, maternal and child health services would provide a good 'entry point' to identifying and assisting families struggling with mental health related issues.

Forced adoption

11.74 The committee received a number of submissions explaining the long-term mental health impacts of forced adoption and the special need for support and services for women living with the trauma of this experience.

11.75 Origins Inc outlined a litany of appalling practices common during decades of forced adoption, including:

- Denying mothers all knowledge of their legal rights and options,
- Preventing bonding by forbidding the mother to see or touch her baby,
- Forbidding the mother from being discharged until she had signed her baby away,
- Forced suppression of lactation with potent drugs,

81 Catholic Welfare, *Submission 302*, p. 16.

82 City of Port Phillip, *Submission 326*, p. 18.

83 *Submission 326*, p. 17.

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- Unlawful administration of heavy sedation during and post labour,
 - Maltreatment of the mother and treating her in a cruel and demeaning manner,
 - Physically restraining mothers from seeing their babies,
 - Informing mothers that their babies had died at birth when in fact they had been adopted,
 - Using overt and covert methods of coercion to obtain consents to the adoption of the child,
 - Not advising mothers of the permanent nature of adoption.⁸⁴

11.76 The lifetime damage caused by such experiences can be immense, including loss of trust, shame, sorrow, damaged relationships, loss of self-esteem, denial, dissociation, inability to bond with other babies, educational failure and poor employment outcomes.⁸⁵ A range of mental illnesses are related to damage caused by adoption separation, including depression, post traumatic stress disorder, dissociative disorders and panic disorders, alcohol and drug use disorders and personality disorders.⁸⁶

11.77 The personal trauma and pain experienced by mothers decades later were shared with the committee:

I can remember every moment of my time in that hospital and every waking moment the events are in my head and affect my everyday life. I have recently been diagnosed with Post Traumatic Stress Disorder and still suffer from depression that is helped by medication. ... I am currently seeing an excellent Psychologist and having Cognitive Behaviour Therapy, which helps me cope on a day-to-day basis. However, I am not able to be in a social or work situation without becoming extremely distressed and agitated. I am unable to listen to music or watch television and avoid noise as much as possible. I am having flashbacks of both visual and olfactory situations, I have made a personal decision not to drive any more, which isolates me even more, but I do not believe it is safe for other road users for me to be driving while my mind is somewhere else. My dreams are traumatic, both from the deaths of my sons and many other traumatic life events brought on at times by my feelings of having no self-worth and an overwhelming sense of feeling useless in all areas of my life.⁸⁷

11.78 Women talked not only about their personal experience, but of the intergenerational impact of their experience on their other children and family members:

84 Origins Inc Supporting People Separated by Adoption, *Submission 420*, pp [5–10].

85 *Submission 420*, pp 15–18; Name withheld, *Submission 180*, p. 2.

86 *Submission 420*, p. 18; Origins Victoria Inc, *Submission 105*.

87 Name withheld, *Submission 512*, p. 2–3.

Not having been advised that the adoption may cause a lifetime of emotional distress I believed I was being punished by some external force and my second son had died as punishment for 'giving' away my first born. When my third child, a daughter was born, I was suffering from severe depression and a restlessness that has never abated to this day. I woke her every night for approximately 6 years to see if she was still breathing. I went to work when she was 6 weeks old, as I was frightened of her and too emotional to breast feed or care for her properly, I felt. She had a wonderful babysitter, which I am grateful for, but she has suffered emotional problems through her life due to my depression and inability to 'mother' her sufficiently.⁸⁸

11.79 Current mental health services do not necessarily support the needs of these women:

I've suffered major depression ever since and haven't known what to do about it. I tried going to 3 psychologists and even a psychiatrist, and they were all hopeless, they were totally uninformed about the long term effects of adoption loss and all of them re-traumatised me even more. Now I'm afraid to seek out help.⁸⁹

11.80 Origin Victoria called for funding to research the effects of forced adoption, to help minimise the suffering by these women and to help in breaking the 'legacy [for] subsequent generations'.⁹⁰

Children in institutional and out-of-home care

11.81 The committee received many submissions from care leavers: people who spent time in institutional and foster care during childhood. They explained that 'many of the children like me had a terrible experience of institutional life – being subjected to extreme cruelty, deprivation, neglect and abuse'.⁹¹

11.82 Mental illness, related to these childhood experiences, is common among care leavers and suicide rates are high, particularly for male care leavers.⁹²

...many Care leavers have suffered from mental illness for years. We suffer from chronic anxiety; chronic depression; phobias and as well, a large number of us have Post-traumatic Stress Disorder. Our mental illnesses have remained untreated for years because no specific treatment programs have been set up to respond to the mental health of Care leavers.⁹³

88 Name withheld, *Submission 512*, p. 2.

89 Name withheld, *Submission 145*, p. 1.

90 Origins Victoria Inc, *Submission 105*, p. 11.

91 *Submission 370*, p. 1 (received from 182 care leavers).

92 Broken Rites (Australia) Collective Inc., *Submission 340*, p. [5].

93 *Submission 370*, p. 1 (received from 182 care leavers).

11.83 In August 2004 the Senate Community Affairs References Committee presented its comprehensive and compelling report on Australians who experienced institutional or out-of-home care as children. Readers are referred to that report for a better understanding of the horrific experiences endured in out-of-home care, and the lifelong impacts of those childhood experiences on care leavers, their children, families and communities.

11.84 Among the many important recommendations made by that committee are recommendations aimed at addressing the mental health care needs of care leavers. However, this committee was informed that:

...the majority of organisations that are responsible for the untreated mental illness that we now suffer, have chosen not to respond to our needs and choose not to set up services responsive to our identified and documented needs.⁹⁴

11.85 The Australian Government responded to the Community Affairs References Committee's report in November 2005, acknowledging '[t]he suffering experienced by so many children placed in institutional care is a matter of shame for this country'. The Australian Government stated that '[t]o those whose experiences have scarred them indelibly, we as a nation need to respond with appropriate help',⁹⁵ but pointed out that many of the recommendations were a matter for state and territory governments. The federal government noted that it had provided a one-off \$100,000 grant to the Care Leavers of Australia Network (CLAN) for counselling services for care leavers.⁹⁶

11.86 Subsequently, the Senate resolved to request that the governments of each state and territory respond to the report's recommendations.⁹⁷ The responses received have been tabled in the Senate.

11.87 Without specialised mental health services, care leavers are largely reliant on public mental health services.⁹⁸ However, as public services are stretched responding to those in acute phases of illness, particularly those who are suicidal, care leavers are a group at risk of missing out on mental health care.⁹⁹

94 *Submission 370*, p. 1 (received from 182 care leavers).

95 Australian Government, *Australian Government Response to the Committee's Reports: Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children and Protecting Vulnerable Children: A national challenge. Second report on the inquiry into children in institutional or out of home care*, p. 3.

96 Australian Government, *Australian Government Response to the Committee's Reports: Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children and Protecting Vulnerable Children: A national challenge. Second report on the inquiry into children in institutional or out of home care*, pp 10 and 12.

97 The Senate, *Journals*, 29 November 2005, p. 1442.

98 Broken Rites (Australia) Collective Inc., *Submission 340*, p. [6].

99 *Submission 340*, p. [4].

11.88 As well as services directed to care leavers, targeted services are also required for people supporting children living in out-of-home environments today. AICAFMHA reported that children under the care of the state have unique difficulties and are highly vulnerable, resulting in more mental health problems that can include severe and long-term mental illness.¹⁰⁰ Foster parents need training and skills to best understand their roles and provide specialised support, given the often complex situations that have been previously encountered by the children placed in their care.

Vietnam veterans

11.89 The sons and daughters of Vietnam Veterans have a much higher rate of suicide than the general population in a similar age bracket, and are more likely to suffer from depression.¹⁰¹ The Department of Veterans' Affairs has implemented a number of initiatives to increase the support available to veterans and their families, including a counselling service targeting the specific needs of this group. It is important that long-term damage to the mental health of people returning from conflict situations is understood in the context of consequential impacts on families:

By preventing or minimising mental illness among veterans of Rwanda, Somalia, East Timor, Bougainville, the Solomon Islands, Afghanistan and Iraq, government may also prevent consequent mental illness among their sons and daughters.¹⁰²

... we need to know we will be the last generation to face this. We need to know that the Defence Force is paying more attention to psychological care for troops returning from battle, both immediately after service and for some years thereafter.¹⁰³

Child and domestic abuse

11.90 The link between sexual assault, child abuse, domestic violence and poor mental health outcomes is well established.¹⁰⁴ It is estimated that around 50-55 per cent of women with mental health problems or disorders are victims of child sexual abuse. For some illnesses, such as personality disorders and dissociative disorders, the prevalence rate is as high as 70-80 per cent.¹⁰⁵

In American patients diagnosed with BPD [Borderline Personality Disorder], 40-70 per cent report the childhood experience of sexual abuse alone. In persons with co-morbid PTSD [Post Traumatic Stress Disorder]

100 AICAFMHA, *Submission 83*, p. 18.

101 Ms Anne Matheson and Dr Anthony Marinac, *Submission 40*, p. 1.

102 *Submission 40*, p. 5.

103 *Submission 40*, p. 7.

104 Women and Mental Health Inc, *Submission 310*, p. 4; Merinda Epstein, *Submission 207*, p. 15; Newtown WDVCS: Marrickville Legal Centre, *Submission 51*, p. 2; Rob Moodie, *The health Costs of Violence – A Summary of Findings*, Victorian Health Promotion Foundation, 2004.

105 Women and Mental Health Inc, *Submission 310*, p. 3.

and BPD and who have experienced various forms of childhood trauma and abuse, the suicide rate is double that for persons with PTSD alone.¹⁰⁶

11.91 The strong link between child abuse, domestic violence and mental illness has important implications for service response and clinical treatment. For example, Women and Mental Health Inc note that:

...considerable skill is required to interpret disclosures [of sexual assault] presented by people who are experiencing a psychotic episode and ensuring that staff understand these disclosures, rather than interpreting them as part of the mental illness.¹⁰⁷

11.92 The mental health impacts of family and domestic violence can continue through generations. Children exposed to domestic violence have a high risk of developing mental illness.¹⁰⁸ Where a mother has been subjected to domestic violence, this can result in ante-natal or post-natal depression, reducing her ability to interact and bond with her child leading to early developmental problems and poor mental health.

11.93 Collaboration between services and long-term supports are needed:

Violence is a complex issue and an interagency approach to safety for women and children experiencing domestic/family violence is fundamental if outcomes for consumers are to be improved. This requires that the mental health sector at all levels of the mental health hierarchy, actively support and sustain collaborative engagement with other agencies. Resolution of violence issues takes time and this requires that mental health change its focus to sustained involvement with some families.¹⁰⁹

11.94 Mental health services are required that are responsive to the needs of those who have suffered, or continue to suffer, abuse.

Concluding remarks

11.95 The benefits of having family members as carers are significant, and have been shown to improve health outcomes for people with mental illness. Families are justifiably proud of their achievements in caring for one, or quite often multiple, family members with mental illnesses:

As a family we are the primary carers for my son who is able to live independently because of the support he receives from us.¹¹⁰

106 Broken Rites (Australia) Collective Inc., *Submission 340*, p. [7].

107 Women and Mental Health Inc, *Submission 310*, p. 2.

108 AICAFMHA, *Submission 83*, p. 18.

109 Women and Mental Health Inc, *Submission 310*, p. 5.

110 Name withheld, *Submission 95*, p. 1.

11.96 But families as carers, as well as other community members providing care to people with mental illness, need help. Support services should ensure families and carers are able to provide care without feeling overwhelmed in their role, but evidence outlined elsewhere in this report shows that this support is wanting, particularly in the community. There is also inadequate support for carers in the areas of education and training, financial and emotional assistance, and respite. Negative consequences include cessation of their role as carer, inadequate or inappropriate care provided to the consumer, or – as was raised in evidence to the inquiry – the carer develops mental health problems themselves.

11.97 There is evidence that some families may be exposing children to environments which may contribute towards the onset of mental illness or exacerbate its symptoms and effects. Mental healthcare should endeavour to strengthen family relationships and empower all involved members, and recognise that some families may need additional assistance.

11.98 There are a number of programs supporting carers and families in their roles, and it is also clear that the National Mental Health Plan 2003-2008 recognises that the voices of carers should be heard in the formulation of mental healthcare policy, planning and treatment. However, funding over the long term to sustain such programs is not assured, and there appears to be limited effort directed to benchmarking and rolling out effective carer and family services on a national scale. Given the critical role of families and carers in community based care, adequate resourcing must be provided to support this overworked and overburdened group in the community.