Support for Children and Families
Living with a Family Member with Mental Illness

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Thesis submitted in total fulfilment of the requirements for the degree of Doctor of Philosophy (PhD)

March 2016
Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

Signed: Vicki Cowling

Date: 7 July, 2016
Acknowledgements and thanks

I am indebted to the parents, grandparents, foster carer, partner, and young people who participated in this study; they invited me into their homes and contributed their ideas and experiences to improving our understanding of the access to, and influences on, the support they receive, or do not receive. I cannot thank you by name, but learned so much from you.

Meeting with the participants from the families involved was made possible thanks to the commitment and cooperation of Family Support Newcastle Committee of Management, Managers, and the Headin’ Up program team leader, and family workers, who participated in focus groups for the study. My very sincere thanks and gratitude to you all.

To my Supervisors, Professor Mel Gray, Dr Graeme Stuart, and Dr Kylie Agllias (2012-2013) – I acknowledge and thank you most sincerely for your generous guidance, advice, and encouragement throughout my PhD journey.

I also acknowledge and thank staff members from the School of Mathematics and Physical Sciences, The University of Newcastle, for statistical advice.

My family and friends have contributed with their support, interest, and enthusiasm to see me finish, which helped to achieve that goal – thank you so very much!!

__________________________________
Dedication

This thesis is dedicated to all children, young people, parents, partners, siblings, grandparents, relatives, and foster carers who themselves live with a mental illness, or live with a family member with mental illness; and to all those who advocate for greater understanding of mental illness, and for services and supports that are responsive to individual and family needs, and respect culture and country of origin.
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Publication and conference presentations arising from the thesis

Publication


Conference Presentations


___________________________________________________________

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Notes and Abbreviations

Notes

Use of first names only, or pseudonyms - when contributing as authors some parents have chosen to use either their first name only, or a pseudonym, to protect their privacy.

Abbreviations

ABS  Australian Bureau of Statistics.
ACT  Australian Capital Territory
AFCA  Australian Foster Care Association.
AIHW  Australian Institute of Health and Welfare
AASW  Australian Association of Social Workers
COAG  Council of Australian Governments
DOCS  Department of Community Services
FACS  Family and Community Services
FAHCSIA  Families, Housing, Community Services, and Indigenous Affairs
FSN  Family Support Newcastle
LHD  Local Health District
HREC  Human Research Ethics Committee
HREOC  Human Rights and Equal Opportunity Commission
MHCA  Mental Health Council of Australia (now Mental Health Australia)
NAMI  National Alliance for the Mentally Ill
NGO  Nongovernment organisation
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<td>NHMSESC</td>
<td>National Mental Health Strategy Evaluation Steering Committee</td>
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<td>NHWPRC</td>
<td>National Health Workforce Planning and Research Collaboration</td>
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<tr>
<td>NSW</td>
<td>New South Wales (one of the six states in Australia)</td>
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<td>SEWB</td>
<td>Social and emotional wellbeing</td>
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Abstract

The prevalence of mental illness means that many children and adults may be affected at some point in their lives, which, in turn, means that many people may live with a family member who has a mental illness. This case study investigated the support available to, and accessed by, children and families living with a family member with mental illness, in the context of related mental health and family support policies. The thesis was informed by theories of social support, stigma, and recognition, within an ecosystems framework. This exploratory study aimed to understand the lived experience of parents, carers, and family members concerning the sources of the support they received, and their perceptions of factors that facilitated or impeded access to support. The perceptions of family workers were also investigated. Data was gathered from four sources: documents setting out policies concerning mental health and family support; in-depth interviews with family members; focus groups with family workers; and responses by parents and carers to standardised questionnaires. The qualitative nature of the study involved prolonged engagement with parent and carer participants, with two interviews being conducted with them over time.

Analysis of the mental health policies and family support policies at the federal and state (New South Wales) levels highlighted the shift to economic rationalist approaches which have placed increasing responsibility on those who live with someone with mental illness. Analysis also highlighted the complex bureaucracy that families and practitioners needed to negotiate.

Analysis of interviews showed that participants turned first to their family for support, with family workers and other professionals also perceived as supportive. Participants who were mothers wanted to be seen, and strived to be seen, as ‘good’ parents but worried about the child protection service taking their children. Family workers focused on strengths within families, and were perceived to be significant in the support they provided.
This study contributes to an increased understanding of the influences of mental health and family support policies on service providers, and on families with children when a family member has a mental illness. It has also documented the lived experiences of mental illness of mothers, grandmothers and a foster carer, demonstrating their reliance on family, and friends, and awareness of their family needs. The study demonstrates the need for local, accessible community-based services with practitioners who can undertake home visits in a flexible and ongoing way that promotes family strengths and confidence. The methodology and findings of this study contribute to the fields of social work, family services, and mental health.
Chapter 1

Introduction

This study has given voice to a group of people either living with mental illness themselves, living with a family member with mental illness, or both. The participants were clients of a program within a family support agency, Family Support Newcastle, a nongovernment, community-managed organisation receiving funding from various sources. The historical origins of the study lie in the changes in policies and practices of care for people with mental illness over the last half century, when care of the mentally ill shifted from large institutions to the community. Known as deinstitutionalisation, the process found families and communities ill-equipped or unqualified for this caring role.

In Australia, alongside these changes in care arrangements, there have also been successive policies and plans regulating the provision of institutional and community-based mental health services. These have coincided with campaigns for increased public knowledge and understanding to limit the impact of stigma and discrimination against people living with mental illness. Various inquiries and reviews have investigated and brought into the spotlight the sometimes egregious living and financial conditions experienced by people living with mental illness. The most recent review was completed by the National Mental Health Commission in 2014. The Commonwealth government response was published a year later: Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services (Department of Health, 2015).

It is estimated that 45% of the adult population in Australia will experience a mental illness at some time during their life (Australian Bureau of Statistics (ABS), 2008). The most recent mental health survey of children and young people found that 13.9% experienced an emotional or behavioural problem in the 12 months prior to the survey (Lawrence et al., 2015). This is a conservative estimate and the figure is likely to be much higher. Not included in official statistics are the family members affected, especially the children and young people living with a parent with mental illness, and the grandparents and foster carers caring for children of parents living with mental illness, or children who...
have a mental illness. This study focused on families with children, where a family member was living with mental illness. This focus arose, in part, from my involvement in research on children of parents with mental illness since the early 1990s (Cowling, 1999, 2004; Cowling, Seeman, & Göpfert, 2015; Sved Williams & Cowling 2008). This research experience led to an understanding of the lived experience of this group, their parents, and other family members, the exclusion and isolation experienced by many, and the advocacy and participation in awareness raising by young people, their parents who have a mental illness, and other family members.

Most of the children and parents in this study who were affected by mental health issues had a diagnosed mental illness, and this term has been used. Family support is an approach to supporting families, and a specific type of service, such as Family Support Newcastle, and both are used here.

The study aimed to explore the experiences and perceptions of support the family had received and the influences on these experiences, from the perspective of mothers, grandmothers, a foster mother, and other family members, who were participants from the family support agency where the research was conducted. Further, it included family worker perceptions and observations. Interviews and focus groups were the main methods of data collection, along with standardised questionnaires on family coping, communication, and support seeking.

There were two related aspects to this study: the lived experience of mental illness, and experiences of family support, hence the study asked the following research questions:

1. What were the participants’ lived experiences of mental illness?
2. How did participants perceive the relationships and coping ability in their family?
3. Who did participants go to for support?
4. What facilitators and barriers to support did participants identify?

As well as achieving a better understanding of the lived experience of mental illness and the nature of family support received by a group of clients from a particular service, the study also aimed to:

1. Give voice to parents and carers who are living with or caring for a family member with mental illness, concerning their experiences of support they had received and the factors impeding access to needed services.
2. Elicit the perceptions and observations of a group of family workers working with these families in a government-funded nongovernment family support agency, Family Support Newcastle.

3. Add to the growing body of knowledge and understanding of the lived experience of mental illness and its impact on families.

4. Add insights for evidence-based policy and service provision.

Several theories and related research informed the study (see Chapters 3 and 4):

- *Ecosystems theory,* as applied to children and families, views the family as being at the centre of ever-widening social systems and networks, from those closest to the family, such as school and neighbourhood to the broader community, such as health and welfare institutions, and the sociocultural milieu shaping attitudes that impact on these systems.

- *Social support theory* highlights the importance of a strong relational network to the health and wellbeing of people living with mental illness.

- *The theory of stigma* has long been associated with the health and wellbeing of people who experience negative social attitudes; stigma can limit hope, and access to support networks.

- *The theory of recognition,* on the other hand, is a theory of value which maintains that respect and understanding should be foremost in people’s relationships with one another.

A case study framework was used. The overarching design was qualitative as it sought to gain an in-depth understanding of families’ experiences of social support. Rich descriptions accessible through in-depth interviews were sought. As an exploratory study of a heterogeneous group of families it was important that they had the opportunity to describe their experiences freely in a safe environment. Quantitative methods were used to elicit structured self-reports on family functioning and coping ability from the participants. Several parents and carers commented that they had participated as they considered the study important, and hoped their participation would help others in the future. A small number also noted that they did not like completing questionnaires. Participants completed the standardised questionnaires on two occasions, in their own homes with the researcher sitting nearby, so there are possible effects of the demand characteristic of completing the questionnaires in a socially acceptable manner.
Significance of the study

The significance of this study lies in the particular ecological approach taken: beginning with the focus on families and their experiences of services, the policy settings influencing service provision, and their impact on service-users’ and providers’ expectations. The study adds to knowledge about children and families where a family member has a mental illness, contributing to an understanding of relationships within the participating families, the factors that enabled them to access supportive services, or that prevented access, and the important role of family support workers. The study also shows that the group comprising children and families where a family member has a mental illness shares certain characteristics and experiences, while being otherwise diverse in family composition, strengths, and responses to the difficulties they encounter.

The importance of the relationship with family workers has been reported by parents in previous studies. The significance of this role for some families is emphasised here, in their accounts of the support they experienced from their family support workers, who themselves reflected on their positive role with the families. They also reflected on the sometimes negative attitudes towards parents with mental illness, and the patronising attitudes expressed towards themselves by practitioners from other agencies.

The study also highlights the array of bureaucratic, policy, and funding arrangements that shape the experiences of families where a family member has a mental illness. Australia has two tiers of government concerned with the provision of mental health and child and family support services: a federal government, and state (six) and territory (two) governments. Both tiers are involved in the allocation and management of funding, with the delivery of services undertaken by public, private, and nongovernment organisations. Changes in policy directions and funding priorities had a direct impact on the Headin’ Up program from which participants of this study were drawn.
Definitions of key terms

**Adult mental health service**: Public mental health service provided for people aged 19-65 years who meet intake criteria.

**Brighter Futures** is funded by the state government of New South Wales and delivered by nongovernment agencies. The program provides targeted support to vulnerable families with children under nine years.

**Carers** in this study refers to people caring for people with a mental illness.

**Centrelink** is part of the Federal Department of Human Services and is responsible for providing access to eligible individuals and families to social, health, and other payments and services, such as family allowances and pensions.

**Child and adolescent mental health service**: Public mental health service provided for children and young people up to the age of 18 years who meet intake criteria.

**Child and family health nurses** provide a primary health service to mothers in the pre- and peri-natal period. In New South Wales, they are employed by Local Health Districts, such as Hunter New England LHD.

**Child and family health service** is a service for children aged two to 12 years with multiple developmental concerns, who have been referred by another professional. The service is provided in community settings by Hunter New England Local Health District.

**Council of Australian Governments (COAG)** comprises the federal government, and the governments of the six states and two mainland territories, and the Australian Local Government Association. COAG meets to debate and coordinate government activities.

**Commonwealth**: The Commonwealth of Australia is a federal constitutional monarchy under a parliamentary democracy.

**Consumers** refers to those who use health and social services.

**Department of Community Services (DoCS), Family and Community Services** is a Government department in New South Wales which has legislative responsibility for the protection of children, which may include children being taken from their parents and or carers where neglect and or abuse has occurred. Prevention and early intervention services are funded for delivery through nongovernment agencies (see Brighter Futures above).
Family support is a specific type of service, linked with child welfare services, which aims to maintain family unity by providing services to families to strengthen their capacity to meet their own needs. It recognises the importance of a relational network in people’s lives, beginning with a supportive family, friends, peers, and close colleagues and extending to mental health workers and professionals. Research shows that people living with mental illness with strong social and family support fare better than those without these supportive connections. In the context of this study, therefore, it refers to formal and informal networks of support available to people living with mental illness.

Family Support Newcastle (previously Newcastle Family Support Services) is a nongovernment incorporated association that provides counselling and support services to families in Newcastle, New South Wales.

Family support worker is employed by a family support agency to work with families and children to strengthen relationships within the family, and with the community, through practical advice, and a supportive working relationship.

Federal government, also referred to as the Commonwealth or Australian government, is the democratic administrative authority of Australia.

General Practitioner is a medical doctor, who is trained to deliver primary healthcare services in community-based settings.

Living with mental illness: It is increasingly recognised that, for most people, mental illness is episodic. For the most part, people have to cope with their symptoms and their impact on their lives on a daily basis, hence the favoured term, ‘living with mental illness’. This term recognises that acute episodes of mental illness are rare in comparison to having to cope daily with its symptoms. It also implies that these symptoms can be managed with increased understanding and awareness of their impact. This is an important aspect of mental health education and family support plays an important role in this.

Mental health problems refer to diminished cognitive, emotional, or social abilities but not to the extent that the diagnostic criteria for a mental illness are met.

Mental illness is a clinically diagnosable disorder that interferes with an individual’s cognitive, emotional, or social abilities. The diagnosis of mental illness is generally made according to the classifications systems of the Diagnostic and Statistical Manual of Mental
Disorders (DSM) or the International Classification of Diseases (ICD). A person may have a mental disorder but may not have a diagnosis.

**Medical model** refers to a model in which professional clinical experts make diagnoses and recommend treatment on the basis of judgements about a patient’s symptoms and their accounts of them. It is often critiqued for focusing on deficits, and overlooking psychosocial and spiritual factors.

**Northern Settlement Services** are an independent not-for-profit entity offering a variety of settlement services to refugees and migrants of non-English speaking backgrounds, in parts of the state of New South Wales.

**Reconnect** is funded by the Federal Government Department of Families, Housing, Community Services and Indigenous Affairs, and delivered by nongovernment agencies. Reconnect assists young people to engage or re-engage with family, education, and their community.

**Recovery**: Personal recovery concerns self-determination, and identity beyond diagnosis; recovery models acknowledge the importance of the lived experience of mental illness. This means a privileged focus on the patient’s perspective and experience that has too long been subordinated in medical, diagnostic models of care where the disorder and its symptoms is the focus rather than the person experiencing it.

**Salvation Army** is a Christian denomination which delivers an extensive range of services to individuals and families of all ages.

**Samaritans** is a social welfare organisation of the Anglican Diocese of Newcastle, New South Wales.

**Severe mental illness** is characterised by a severe level of clinical symptoms and degree of disablement to social, personal, family, and occupational functioning.

**State government**: government in Australia of the state of New South Wales, Queensland, South Australia, Tasmania, Victoria, Western Australia.

**Territory government**: government in Australia of the territory of Australian Capital Territory (ACT), or the Northern Territory (NT).

**Young carers** are children and young persons under 18 who provide, or intend to provide care, assistance or support to another family member.
Overview of the thesis

This chapter has presented the background to the study providing a brief overview of the historical and policy context, and the research aims. The next chapter describes the population group under study, while Chapters 3 and 4 outline the theoretical background to the study. Chapters 5 and 6 examine the policy and service context relating to mental health and family support, respectively. Chapter 7 presents the study’s methodology and Chapters 8, 9, and 10 present the study’s findings. The main findings of the study are discussed in Chapter 11 with Chapter 12 drawing conclusions and recommendations from this study, and their implications for policy and research.
Chapter 2

Children and adults living with a family member with mental illness

In mental health and associated fields of practice, there has been an increasing emphasis on interventions to improve the health and wellbeing of adults living with mental illness and, more recently, the parents and family members who may have a caring role for them. This is due to the advocacy of carers and professionals who have recognised the caring role and associated needs of these family members (Bland & Foster, 2012; Falloon, 2003; Wright, 2014). This approach has focused on some family members more than others. Two groups that have been the focus of increasing research in the past two decades are: (i) children of parents with mental illness (Beardslee, Gladstone, & O’Connor, 2011; Gladstone, Boydell, Seeman, & McKeever, 2011; Sved Williams & Cowling, 2008) and (ii) parents living with mental illness and raising dependent children (Göpfert, Webster, & Seeman, 2004; Nicholson, Sweeney, & Geller, 1998). Other family members who have received relatively less attention in research, policy, and service development include parents and siblings of children with a mental illness, partners or spouses of parents with a mental illness, grandparents caring for their grandchildren when a parent has a mental illness, and foster parents caring for a child or children with mental illness. In Australia, the historical and cultural context and experience of Aboriginal and Torres Strait Islander peoples influences the way in which they care for a family member with mental illness, and this has also been a focus in research, policy, and practice.

This chapter discusses these groups to provide a backdrop against which the experiences of the study participants can be considered to counter homogeneous portrayals of families living with, and affected by, mental illness; it illustrates the diversity of contextual experiences affecting such families. Parents with a mental illness, grandparents, foster parents, young people, and partners or spouses have contributed first-person accounts in published books and journals, motivated by the wish to add to knowledge and understanding of their lived experiences and provide insight into the common and variable impacts of mental illness on different family members. First the prevalence of mental
illness occurring for adults and children is discussed, and then available data on the number of family members affected, such as partners, children, siblings and others is presented. Each group is then examined in terms of statistics on those affected, where they are known, examples from available research, and personal accounts illustrating the lived experience of individuals from that group.

Prevalence of mental illness

In Australia, it is highly likely that almost every member of the population will encounter someone living with mental illness in their family, workplace, or community. In the most recent survey of the mental health of the adult population in Australia, using self-reports based on the International Classification of Diseases (WHO, 2010), an estimated 45% of people aged between 16 and 85 years met the criteria for a diagnosis of a lifetime mental disorder, or a mental disorder at some time in their life, that is, 7.3 million people (Australian Bureau of Statistics (ABS), 2008). The 12-month prevalence rate, or the proportion of the population who met criteria for diagnosis of a mental disorder at the time of the survey, was 20% or just less than 3.2 million people (ABS, 2008). Table 2.1 shows estimates, by age group, of the adult population affected by mental illness in a survey conducted by the ABS (2008), with information collected from approximately 8,800 Australians aged between 16 and 85 years, relating to high-prevalence mental disorders, such as anxiety, depression, and substance use disorders. Respondents may have met the criteria for more than one diagnosis. Analysis of family household composition showed 34% of respondents living in a sole-parent family with children met the criteria for a diagnosed mental disorder in the 12 months prior to the survey, compared with 19% of respondents living as a couple family with children, and 14% of couple-only (or childless) households (ABS, 2008).

Sawyer et al. (2000) examined the prevalence of mental health difficulties occurring for Australia children and adolescents aged between four and 17 years and found that 13% scored in the clinical range for externalised symptoms, such as aggressive or delinquent behaviour, and internalised problems, such as anxiety or depression.
Table 2.1: 12-month prevalence of mental disorders in people aged 16-85 years

<table>
<thead>
<tr>
<th>Age group in years</th>
<th>%&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Estimated population&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 – 24</td>
<td>26</td>
<td>671,100</td>
</tr>
<tr>
<td>25 – 34</td>
<td>25</td>
<td>698,400</td>
</tr>
<tr>
<td>35 – 44</td>
<td>23</td>
<td>716,400</td>
</tr>
<tr>
<td>45 – 54</td>
<td>21</td>
<td>613,700</td>
</tr>
<tr>
<td>55 – 64</td>
<td>14</td>
<td>316,700</td>
</tr>
<tr>
<td>65 – 85</td>
<td>15</td>
<td>181,500</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>-</strong></td>
<td><strong>3,197,800</strong></td>
</tr>
</tbody>
</table>

<sup>a</sup> A person may have had more than one mental disorder (ABS, 2008).
<sup>b</sup> Estimated number of people aged between 16-85 years in Australia with symptoms of mental disorder in the 12 months prior to the survey.

Lawrence et al. (2015) found that 13.9%, or the equivalent of 560,000 children and young people experienced an emotional or behavioural problem in the 12 months prior to their survey. They noted that, while the prevalence rate was much the same as that found in Sawyer et al.’s (2000) survey, the rate of depression had increased, while ADHD and conduct disorder had decreased. One sixth (17%) of all children and adolescents aged between four and 17 years had used services for emotional or behavioural problems in the previous 12 months. Information about the children and young people was provided by parents or carers who completed standardised questionnaires, with children 11 years and over having the opportunity to complete a questionnaire on a tablet computer (Lawrence et al., 2015). Parents and carers of the children and adolescents surveyed were asked whether they or other family members had received help and whether or not their needs had been met; if not, they were asked about the type of help they needed. Among those parents and carers who needed help (61%), one in five said they had unmet needs, such as counselling to help them with managing their child’s problems and family relationships, as well as counselling to help them manage their own stress and worry arising from their child’s difficulties (Lawrence et al., 2015).

**Number of family members of people with a mental illness**

The populations of interest in this study were family members who lived with a child or parent with a mental illness: parents, grandparents, foster carers, and siblings living with a child with mental illness, children who live with a parent with mental illness, and partners living with a parent with mental illness. However, little is known about the numbers...
affected as this data is simply not available (see Table 2.2), indicating a lack of recognition of most of these groups and a homogenisation of the mental health experience. The focus of research concerning support for families living with a family member with mental illness has been on the care of an adult by other adults in the family, such as parents or siblings (Falloon, 2003).

### Table 2.2: Family members of people with mental illness

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of family members identified as carers</th>
<th>Number of family members affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults living with an adult family member with mental illness</td>
<td>Not known (Mental Health Council of Australia, 2009)</td>
<td>Not known</td>
</tr>
<tr>
<td>Siblings of a child with mental illness</td>
<td>Not known</td>
<td>Not known</td>
</tr>
<tr>
<td>Parents and carers of a child with mental illness</td>
<td>Estimate 560,000 (Lawrence et al., 2015)</td>
<td>Not known</td>
</tr>
<tr>
<td>Children and young people of a parent with mental illness</td>
<td>Not known, although 3.2% of all carers under 18 in Australia have been identified as primary carers (Noble-Carr, 2002).</td>
<td>Estimated one million Australian children (Maybery, Reupert, Patrick, Goodyear, &amp; Crase, 2009).</td>
</tr>
</tbody>
</table>

In some cases, rough estimates can be made from the ABS (2004) data, which indicated there were about 2.6 million carers in Australia for people with various physical, intellectual, and mental health difficulties. The first national survey of mental health carers (Mental Health Council of Australia, 2009) suggested this was an underestimate, based on the number of people who reported having experienced a mental disorder at some time in their lives (7.3 million), or during the 12 months prior to the National Survey of Mental Health and Wellbeing (3.2 million) (ABS, 2008).

The following section presents an overview of contemporary research in this area, citing representative studies only for each of the identified family groups who might have been encountered in this study:

1. Parents with a mental illness who have dependent children.
2. Partners of parents with mental illness.
3. Children and young people of parents with mental illness.
4. Parents caring for children with mental illness.
5. Siblings of children with mental illness.
6. Grandparents parenting grandchildren of parents with a mental illness.
7. Foster carers of children with mental illness.
8. Aboriginal families living with a family member with mental illness.

The search strategies followed to locate literature for this chapter included library database searches, searches of grey literature, websites, google and google scholar, and reference lists in related journal articles. The search strategies used in the thesis are set out in Appendix I.

**Research on families living with a mental illness**

Research relating to the eight groups identified in the literature is generally limited, although two groups have been the focus of study in recent times: parents with dependent children who have a mental illness, and the children of parents with mental illness. Examples of studies which have examined issues for parents include surveys (Nicholson, Nason, Calabresi, & Yando, 1999; Targosz et al., 2003), program evaluations (Nicholson, Albert, Gershenson, Williams, & Biebel, 2009), and qualitative studies (Diaz-Caneja & Johnson, 2004; Zemencuk, Rogosch, & Mowbray, 1995). Examples of studies of children of parents with mental illness have included reviews (Gladstone et al., 2011; Siegenthaler, Munder, & Egger, 2012), qualitative studies (Aldridge & Becker, 2003), and evaluation of an intervention (Reibschleger, Tableman, Rudder, Onaga, & Whalen, 2009). The family unit has been the focus of one longitudinal study of an intervention designed for families where a parent with dependent children had depression (Beardslee, Wright, Gladstone, & Forbes, 2007). The following sections discuss research relating to each of the eight groups in turn.

**Parents with a mental illness who have dependent children**

Estimates based on combining data from the ABS (from surveys conducted in 1997 and 2003) and the mental health office in the state of Victoria (using statistics from the 2003-2004 financial year) indicated there were approximately 577,500 sole and two-parent families in Australia with at least one parent experiencing a mental illness judged as
‘severe’ to ‘not severe’ (Maybery et al., 2009). Parents with a mental illness caring for dependent children were more likely to be on a low income, a sole parent, and socially isolated (Targosz et al., 2003). Targosz et al. (2003) interviewed over 5280 women in the UK, with 612 being single mothers; 30% had at least one mental disorder, compared to 20% of supported mothers (those who shared their household with at least one other adult), and more than three times as many single mothers were classed as having two or more disorders than was the case for supported mothers (Targosz et al., 2003). In the six months preceding the survey, 15.4% of the single mothers had experienced three or more stressful life events, compared to 6% of the supported mothers, and 13% reported a ‘severe lack’ of social support, compared to 8% of supported mothers.

Smaller studies of mothers have included structured interviews (Zemencuk et al., 1995), semi-structured interviews (Diaz-Caneja & Johnson, 2004), focus groups (Bassett, Lampe, & Lloyd, 1999; Nicholson, Sweeney, & Geller, 1998), and program evaluation (Nicholson et al., 2009). These studies found motherhood was an important role for women, being central to their sense of self-worth, and having children helped to focus their lives (Diaz-Caneja & Johnson, 2004; Zemencuk et al., 1995). The challenges for mothers with mental illness were the stigma of mental illness, managing their mental illness along with day-to-day parenting (Diaz-Caneja & Johnson, 2004; Nicholson et al., 1998), and worry that their children would also suffer from mental illness in the future (Diaz-Caneja & Johnson, 2004). The interventions that parents suggested would help them included having links with community agencies for support in their role as parents, and community support, such as access to public transport and respite care (Bassett et al., 1999). These support needs were reflected in the evaluation of a program for parents and children in which the 22 participating parents (all mothers) responded that the most important aspects of the program were practical, including help with transportation and recreation, and with obtaining services and benefits (Nicholson et al., 2009).

Fathers with mental illness have received relatively little attention in research and intervention studies, but a significant proportion of fathers with mental illness live with their natural, step, adopted, or foster children (Fletcher et al., 2012). Two recent studies on fathers found they endeavoured to be good fathers, and valued their relationships with their children (LeFrançois, 2010; Reupert & Maybery, 2009). Reupert and Maybery (2009) conducted qualitative interviews with 11 fathers and found that, while none lived with their children, fatherhood was important to them. They identified strongly with the image
of fathering, and valued their relationships with their children, although some had experienced disputes over child custody following separation, and there were varying experiences of ongoing contact with their children. A review of 31 studies from four countries by LeFrancois (2010) found that those fathers diagnosed with psychosis were fearful that their children would develop a psychotic disorder, and would suffer the same stigma they had experienced. The fathers took pride in their fathering role, and indicated that their relationships with their children were important to them, and led them to try harder to recover and change some of their maladaptive coping strategies (Evenson, Rhodes, Feigenbaum & Solly, 2008, cited in LeFrancois, 2010). Fathers in both studies were reluctant to seek help and treatment (LeFrancois, 2010; Reupert & Maybery, 2009), due to stigma, which also influenced decisions about contact visits with their children (Reupert & Maybery, 2009). They also experienced prejudice and discrimination, harassment, verbal abuse, and social exclusion, and were fearful their children would be taken from them by child protection agencies (LeFrancois, 2010).

First-person accounts of parenting while managing symptoms of mental illness reveal the important part children play (Amy, 2008; Fox, 2009; Kelly, 1999). For example, in her account, Kelly (1999) captured the struggle and challenge for parents: ‘nowhere is the hope, despair, triumph and complexity of life more clearly illustrated than in our endeavours for our children – and mental illness pushes these experiences to extremes’ (p. 60). Kelly (1999) described the many losses a parent might experience due to mental illness, including loss of life expectations, loss of contact with children, loss of self-esteem, loss of income, loss of rights, loss of fulfilment and, for some, loss of hope. She proposed that an effective response was one that focused on the needs of children and parents in the family unit.

**Partners of parents with mental illness**

Armitage (in Cowling, Edan, Cuff, Armitage, & Herszberg, 2006) noted an absence of statistics on the number of partners of parents with a mental illness, where there were dependent children, although the mental illness experienced by one partner would impact on the other, and on their children. Research on adult family members caring for a partner with a mental illness gives some insight into the needs of this group. A national survey of mental health carers identified 15 key issues affecting partner-carers, including the following: they felt isolated and helpless and lacked knowledge about mental illness; they
felt ignored and patronised by professionals who did not seem to understand their role as carers; there was a lack of service and support programs available for them; and there was limited acknowledgement of their physical and mental health needs arising from, and affected by, their caring role (Mental Health Council of Australia, 2009). The impact on partners might include worry about the unwell parent, and about the children, which has been described by three partners in their personal accounts (Armitage, in Cowling et al., 2006; Karen, 2008; Williams, 2008). In the experience of one of these partners:

When a family develops a mental illness, the effects of the illness do not confine themselves to the unwell person. In our family, my partner’s illness was a calamity for the whole family … For more than 4 years we lived in the crisis. It almost destroyed us as a family. Our family was affected in so many ways. As parents, the worst moment for us was when we realised our 7-year-old daughter was suffering emotional injury and herself needed counselling. I very seriously considered abandoning my unwell partner and removing the children to protect them. I remember very well my feelings of frustration, exclusion, isolation, despair and exhaustion … The welfare of our family seemed to be solely my burden. I felt largely removed/excluded from the process of my partner’s treatment, yet we as a family were daily suffering with her the effects of her illness (Armitage, in Cowling et al., 2006, p. 416).

A partner’s need to support the unwell parent might lead to a struggle to understand the feelings of hopelessness of the parent, and to themselves becoming ‘emotionally numb’ (Williams, 2008, p. 84). Williams (2008) described having to be strong enough to know that his partner’s depression was not his fault, and to accept that he could not do much about it: ‘All the things we used to do together, all the things I could do to cheer her up, just don’t work anymore. I’m so lost’ (p. 83). He realised that trying to be strong meant he was blocking out bad feelings and ‘fun feelings’, and, in hindsight, realised his partner ‘needed to see me cry as part of her own healing. She needed to hear my worries and concerns to know that hers were valid’ (p. 84).

In other cases, a misdiagnosis, or lack of diagnosis, might lead to ineffective treatment, leaving the partner and children confused by the angry moods and unpredictable behaviour of the parent with mental illness (Karen, 2008). Karen’s (2008) husband was diagnosed with, and wrongly treated for, depression for many years, when, in fact, he had
bipolar disorder. Things improved with this correct diagnosis. Karen described her experience as being:

   Very hard at times, trying to run a household, look after the (four) children, and also deal with the illness … My children have suffered a lot due to Rob’s illness. The moods, the anger, the disappointment when we have to cancel family outings (Karen, 2008, p. 85).

   Distress was also related to poverty arising from loss of income (Hawkins, 2014). Kerry Hawkins (2014) and her three children lived with their husband and father whose paranoid beliefs led him to flee from Australia periodically, attempt suicide twice, seek admission to inpatient units, and take ineffective medication. Over several years, Hawkins (2014) supported her husband, and believed in him; she believed that, as the father of their children, he was the only person who could heal them from the trauma associated with his illness. She found the emotional and practical strains as ‘indescribably challenging’ (p. 17). She gave up her job to support her husband, having little confidence in mental health services to support him in recovery, and to be available for her children. Eventually the involvement of a peer worker ‘who didn’t tell my husband what was wrong with him but asked, ‘What happened to you?’ (p. 17), empowered and supported the family to work out what they needed, and to access the required resources. Hawkins (2014) described her husband as resuming his life in the community, and his place in the family, with full awareness of the effect of his illness on the children, ‘with his presence healing them in a way nothing else could’ (p. 17).

   For three of the partners cited above – Williams, Karen, and Hawkins – finding someone to talk to was invaluable in relieving stress and providing reassurance. This support might have come from an understanding clinician, a support group for family members, or a peer support worker (Karen, 2008).

**Children and young people of parents with mental illness**

Information is lacking concerning the number of children and young people in Australia who have the role of primary carer for a parent or family member with mental illness. Estimates based on Australian Bureau of Statistics survey data from 1998 found that 18,800 young people under 26 years were primary carers. Approximately one quarter of
this group provided care for someone with a mental illness, a figure which ‘is likely to be an underestimate’ (Noble Carr, 2002, p. 11).

Maybery et al. (2009) estimated that over a million children in Australia had at least one parent with a mental illness, representing 23.3% of the population of children aged 0-17 years. Fudge and Robinson (2009) claimed a range of factors contributed to the degree to which a parent’s mental illness might impact on a child, including genetic inheritance, psychosocial adversity, family relationships, and connection with the community.

Reviews of literature have been conducted relating to children’s experiences of parental mental illness (Gladstone et al., 2011), and to children’s self-expressed strengths and resources (Drost, van der Krieke, Sytema & Schippers, 2015). Gladstone et al. (2011) reviewed qualitative research on children’s experiences of parental mental illness. They located and analysed 20 studies, 10 of which focused exclusively on children’s descriptions of their experience of parental mental illness and the remainder examined adult family members’ perspectives. Children in the studies included in the review were aged between five and 18 years; in all age groups ‘children reported knowing something was wrong even when parents had tried to suppress their illness-related difficulties’ (Gladstone et al., 2011, p. 285). Children reported, paradoxically, that while school acted as a refuge, they also had to manage the bullying behaviour of others, and sometimes their deteriorating academic progress. They were aware of stigma and the negative beliefs of others, and while they might have had little knowledge about their parent’s mental illness, they hid the family situation from friends so as not to risk ‘losing’ their friendship (Gladstone et al., 2011). Drost et al. (2015) reviewed 26 studies which focused on self-report experiences of children, identifying their subjective strengths and resources. The self-reported strengths of the children were their experiences of themselves as more mature, independent and empathic than their peers, and as having acquired abilities such as being able to accomplish difficult tasks. The self-reported resources included recognition by professionals of their role in supporting their parents; being invited to family meetings where information about their parent’s illness was discussed, and practical help with finances and housekeeping (Drost et al., 2015).

The experiences of children and young people have also been described in first-person accounts (Bilsborrow, 2015; Carr, 2004), and in a study of 40 young carers of parents with a mental illness (Aldridge & Becker, 2003). Adults who grew up with a parent
with a mental illness have also provided personal accounts (Blair, 2004; Hinshaw, 2002; Roberts, 2004), with others reporting qualitative research studies of adults who grew up with a parent with a mental illness (Camden-Pratt, 2006; Dunn, 1993; Foster, 2006).

In her personal account, Miriam Carr (2004) described herself as a 17-year old as having similar interests to other young people her age, though her life was very different because her mother had a bipolar disorder. While not miserable, life had been extremely difficult at times. Her mother sometimes slept a lot and became withdrawn. However, Miriam had not wanted her to feel guilty ‘or to think that she has been a bad mum, but at times a sick one’ (Carr, 2004, p. 77). Alongside her love and concern for her mother, she described feelings of loneliness and embarrassment. Not always understanding how her mother’s symptoms affected her led to her wanting to work ‘with organisations to help educate people about depression’ (Carr, 2004, p. 78) once she left school.

Bilsborrow (2015) interviewed six young people wanting to understand their parent’s ill health, so they could then understand their disconcerting behaviour. One participant wondered ‘why she [meaning her mother] cried so much, and why she said and did strange things. [Had I understood] I might not have worried so much that I would become like her’ (p. 4). These young people wanted mental health practitioners to introduce themselves when they visited their parent at home, to keep them informed and tell them what was going to happen as they lived with and knew their parents and were sometimes expected to keep their parent’s medication out of reach: ‘[The doctor went upstairs to see mum] and when he came back down he handed me all her tablets and told me not to let her have any of them’ (Bilsborrow, 2015, p. 18). This young person had been brushed aside by the doctor on arrival, who said he wanted to speak to an adult, other than the mentally ill parent. There was no other adult, so the doctor just assumed the young person would be responsible for his, or her, mother’s medication.

In Australia, Foster (2006) examined the childhood experiences of 10 adults with a parent with mental illness. She found that the participants had received little or no information about their parent’s mental illness when they were children, and experienced high levels of what Foster (2006) referred to as ‘parentification’, a role reversal in which children took on the care of their parents. An earlier study by Dunn (1993) had likewise found that adult children had received little information about their parent’s illness, and had had negative experiences with health professionals.
Parents caring for children with mental illness

As noted above, Lawrence et al. (2015) recently reported that 13.9% of Australian children and young people aged between four and 17 years had experienced an emotional or behavioural problem in the 12 months prior to their survey, that is, 560,000 children and young people and, by association, their parents and carers. Higher rates of mental disorders experienced by children and young people in the 12 months preceding the survey were found to be associated with family composition (living in a step, blended, or sole-parent family), low family income, the unemployment of a parent or carer, and levels of family functioning as assessed by the short-form McMaster Family Assessment Device-General Functioning, used in the present study (discussed in Chapters 7 and 10). Just over a third of young people in families with poor family functioning had a mental disorder. Smaller proportions of young people in families with good, or very good family functioning also had a mental disorder (Lawrence et al., 2015).

Meltzer, Ford, Goodman, and Vostanis (2011) noted the paucity of evidence relating to the burden of children’s emotional and behavioural difficulties on their parents. They used data from interviews with parents (and in some cases young people and teachers) on 10,438 children aged between five and 15 years in Great Britain to describe the problems experienced by parents. The children were diagnosed with conduct or emotional disorders, or co-occurring disorders. Parents of children with conduct disorders reported feeling worried (90%), depressed (66%), or tired (75%), with between 25-50% of parents going to their general practitioner for help, and two-thirds of this group being prescribed medication (Meltzer et al., 2011). Mendenhall and Mount (2011) reported similar findings following a review of literature on the biopsychosocial impact of mental illness in children on their parents, also noting impacts on work and social life. They found formal and informal online interventions to address parent or caregiver needs included: education about symptoms and their treatment, family-focused therapy, and parental behaviour-management skills development. In an earlier study, Marsh and Johnson (1997) reported similar findings on family experiences of serious mental illness, in which parents also identified several other interventions, such as problem-solving and stress-management skills development to help them cope with their child’s symptoms.

A few studies have reported on the impact of childhood emotional disabilities on families though most have focused on families with a child with a physical disability, or
families where an adult psychiatric disorder was present (Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998). Survey studies that have examined the impact of childhood emotional disabilities on families have found negative impacts on siblings, who have less time with their parents, and on the family unit’s social life and relationships with family and friends. They also put a strain on spousal or partner relationships and the mother’s health (Angold et al., 1998; Friesen, 1989). Yatchemoff et al.’s (1998) study on the impact of childhood emotional disorder on 214 families found that family enrichment (social support, financial resources, formal support, and belief in family capacity to influence life events) was associated with positive self-concept and family relationships, while family stress was associated with the severity of the child’s disorder, parental feelings of disempowerment, and lack of coordination among service providers.

**siblings of children with mental illness**

The Human Rights and Equal Opportunities Commission’s (HREOC, 1993) investigation on the rights of people with mental illness found that procedures in mental health services did not require the systematic collection of information about the siblings of children referred for service. There were thus no official statistics on the number of children under 18 years of age who have a sibling with a mental illness. This situation remains unchanged. During the mental health assessment process, practitioners might record information on the child’s family, including number, gender, and age of siblings, but these records were not accessible to researchers or others engaged in formal data collection due to privacy issues (HREOC, 1993).

In recognition of the lack of attention to siblings within the service system, Kilmer, Cook, Taylor, Kane, and Clark (2008) conducted structured interviews with parents (or caregivers) to compare 56 siblings of a child in the family who had a mental illness on measures relating to emotional strength and adjustment. One in six siblings was found to have a high susceptibility to an emotional or behavioural disorder; a significant minority displayed higher levels of problem behaviours than their siblings who were receiving treatment. Family cohesion and positive support networks acted as a buffer in siblings who showed emotional strength and positive social-emotional adjustment (Kilmer et al., 2008).

Three studies examined the wellbeing of siblings of children with autism: One compared them with siblings of non-disabled children (Macks & Reeve, 2007); the second
compared them with siblings of children with Down Syndrome and of normally developing children (Kaminsky & Dewey, 2002); and the third compared them with siblings of children with mental retardation and developmental language disorder (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Each study used a convenience sample, with children being compared on measures of behaviour and emotional adjustment. Two studies directly involved the children, by asking them to complete standardised questionnaires (Kaminsky & Dewey, 2002; Macks & Reeve, 2007). All studies used standardised questionnaires to collect study data from parents. The siblings were found to be functioning well emotionally (Pilowsky et al., 2004; Kaminsky & Dewey, 2002), with enhanced psychosocial and behavioural development where demographic risk factors were low (Macks & Reeve, 2007). Kaminsky and Dewey (2002) found that siblings of children with autism were well-adjusted. They reported low levels of loneliness and high levels of social support from their parents, teachers, and close friends. Parental participation in support groups for families of a child with autism may have contributed to these positive outcomes (Kaminsky & Dewey, 2002).

Accounts of the experiences of children and young people living with a sibling with mental illness were limited at the time of the enquiry into the human rights of people with mental illness referred to above, but HREOC (1993) reported one example:

You are hurt and embarrassed. You feel you want to do something to help your sister but as a child you feel there is nothing you can do. You feel guilty because you hate her and you don’t really know what is wrong with her. No one tells you when you are a child, certainly not the psychiatrist. Lack of understanding is seen in teasing at school: ‘Guess who’s got a mad sister?’ the kids scream (Written submission, HREOC, 1993, p. 472).

Another submission by professionals to the enquiry highlighted further issues for children:

Brothers and sisters may suffer bewilderment, fear, ambivalent feelings of resentment and sympathy, the disruption of their home life and stress on their studies. Social activities may be curtailed by a reluctance to bring friends home. Parents sometimes forbid the other children to talk about the problem outside the home, relatives and friends stop calling, and the tension between parents who feel
guilt and anger creates intolerable burdens for the whole household (Written submission, HREOC, 1993, p. 472).

This is emphasised further in personal accounts and memoirs of growing up with a sibling with a mental illness. Clea Simon was eight years old when symptoms of schizophrenia were first experienced by her older brother and sister (Simon, 1997). Both had received a formal diagnosis of schizophrenia by the time she was 10 years old. She described the increasing illness of her siblings, the fragmenting effect on her family, and feeling abandoned by her parents as they focused on her siblings. Similar experiences are described in *Divided Minds*, the dual memoir of identical twin sisters, written in the alternating voices of each (Spiro Wagner & Spiro, 2005). Pamela developed symptoms of schizophrenia in adolescence, and her sibling, Carolyn, described her love, frustration, rage, and concern about her sister, and the conflict within the family.

**Grandparents parenting grandchildren of parents with a mental illness**

The 2006 Australian census found that grandparent families, including those with other relatives present, comprised 0.7% of all families (Elliott, 2007). Using a narrow definition of ‘grandparent families’, there were 8,050 families (0.15%) comprising only grandparents with grandchildren under 15 years of age, with 4,780 of these families being couple grandparent families. If a broader definition were used there would have been 63,520 grandparent families having one or more grandparents, one or more grandchildren under 15 years of age, and other family member(s) present (Brennan et al., 2013). The Family Characteristics Survey (FCS) 2009-2010 (Australian Bureau of Statistics, 2011a) reported that in 16,000 grandparent families the grandparents were guardians or main carers of resident children from birth to 17 years of age. The differences in data between the 2006 census and the FCS arose from the differing age range of children, and the limitations of the census, being unable to capture the complexity of family structures and care relationships (Elliott, 2007).

In addition, an unknown number of grandparents as parents are ‘hidden’ and do not access financial and other supports. The grandparents in this group may choose not to identify as the primary caregiver for their grandchildren because their cultural traditions include looking after family members and not seeking help (Commonwealth of Australia, 2009a). A further hidden group are those grandparents who become parents to their
grandchildren when parents have a mental illness (Cowling, Seeman, & Göpfert, 2015). The use of ‘parent’ in this context relies on a social definition of being a parent, which recognises that parenting involves duties, roles, and responsibilities, and is not limited to a relationship based on biology (Sullivan, 2001).

Grandparents become caregivers for their grandchildren for commonly-cited reasons, including physical illness or disability of the parent, substance abuse by the parent, mental illness of the parent, incarceration, or death the parent, military service, family breakdown, or child abuse and neglect on the part of a parent (Baldock, 2007; Families Australia, 2007; Horner, Downie, Hay, & Wichmann, 2007). Grandparents also become caregivers for their grandchildren because they are attached to the children, they feel it is their obligation, or there is no alternative (Cowling, Seeman, & Göpfert, 2015). It is important for services to understand the individual motivations of grandparents.

Grandparents might become parents to their grandchildren when they are infants, and this experience was described in published personal accounts by grandparents Harriet (2008) and Jennifer (2008). In both families, the mothers were unable to care for their babies due to mental illness, and the fathers were also unable to parent their children. Harriet (2008) became the full-time parent to her grandson when he was about a year old. She sometimes resented her loss of freedom, especially when her grandson was young, but also gained ‘great pleasure and satisfaction from caring for [her] only grandchild’ (Harriet, 2008, p. 117). Jennifer (2008) took up the role of parent to her daughter’s two children as ‘foster care was and is not an option’ (p. 107). The younger child was 14 days old when Jennifer took her home, and she would be 70 when her grandson was 10 years old. Jennifer’s home was organised around the children, with the baby sharing her bedroom, her grandson sharing the office, and the lounge room used as a play room. Jennifer received support from a number of services, including her General Practitioner, her son, and her friends, and professional telephone support.

The general literature on the impact of grandparenting grandchildren shows that grandmothers have reported increased stress and depressive symptoms relative to their age-related peers, but less so if their surrogate parenting role were a cultural norm (Dunne & Kettler, 2008), or freely chosen (Giarusso, Du Feng, & Silverstein, 1996). The impact on physical health and finances, and social life and activities has been documented (Brennan et al., 2013), with pre-existing grandparent characteristics influencing the degree of impact (Hughes, Waite, LaPierre, & Luo, 2007).
Brennan et al.’s (2013) survey of 335 Australian grandparents raising their grandchildren found that one third had taken on this role because the child’s parent had a mental illness, and two thirds because of the parent’s drug or alcohol problems (grandparents ticked more than one of the options the survey listed, including child neglect and domestic violence). The grandparents reported that the impact of grandparent care included: financial disadvantage, the need to reduce working hours, or cease working, or change housing arrangements. These changes often involved significant costs, and experiences of social isolation and disrupted friendships. The grandparents also reported that more than 80% of the grandchildren had emotional or behavioural problems, with 50% having physical problems. Approximately two thirds of the grandparents participated in a support group (Brennan et al., 2013). These groups have been found to help grandparents learn from one another about legal rights and financial entitlements, as well as giving them access to social and psychological support (Gerard, Landry-Meyer & Roe, 2006). While support groups reduce stress and isolation, few have been formally evaluated, so evidence of lasting change through grandparent participation in these groups is lacking (Blustein, Chan, & Guanais, 2004).

The grandparents surveyed by Brennan et al. (2013) also accessed other sources of information and support, such as respite care, childcare, and information on helping with schoolwork. However, they reported that finding support was difficult, and required much knowledge and effort on their part. They lacked understanding about their eligibility, and identified parenting gaps. One grandmother explained: ‘My boys are growing up with one elderly grandma. They need regular contact with good male role models’ (Brennan et al., 2013, p. 125).

**Foster carers of children with mental illness**

The Australian Institute for Health and Welfare (AIHW, 2011) defined a foster family as a private household where the carer/s had undergone a selection and approval process, was authorised by the relevant state government department to have children placed in their care, and might be reimbursed by the state or territory government. The AIHW (2015) report for the period 2013-2014 stated that, at 30 June 2014, there were 9,932 authorised foster-care households with a child in care in Australia. Children were generally placed in foster care because their parents were unable to provide adequate care or protection, or because they had been the subject of a substantiation of child abuse or neglect and required
a more protective environment than could be provided with their parents. Substantiation of child neglect or abuse was based on assessment by child protection workers of the level of one or more of the following: physical abuse, sexual abuse, emotional abuse, or neglect (AIHW, 2015). Children might also be placed in foster care as a short-term respite from their birth family or other setting, with the intention they return to that place of residence. A small proportion of children in foster care would not be on a care and protection order (AIHW, 2015).

Searches of the literature did not reveal research on the number of foster parents caring for children with a mental illness, or the specific issues foster carers might face in providing care for these children. This led to a search of the website of the Australian Foster Care Association (AFCA) where a report was located which set out 12 main issues of concern for foster parents, including the need for ‘regular respite and leave entitlements’ and ‘prompt and comprehensive responses when a foster carer contacts a worker’ (AFCA, 2005, p. 20). These issues were relevant to the foster carer who participated in the present study.

Studies that have examined the experiences of foster carers have enquired about the direct and indirect costs and consequences of foster parenting, and the availability of financial and non-financial support. These studies have not differentiated between foster-carers’ experiences of caring for different groups of children, such as children with disabilities or mental health difficulties. The costs to foster carers include financial and time costs, as well as emotional and psychological costs, such as becoming attached to foster children and having to separate when the foster placement ended (McHugh, 2007). Emotional costs also included the impact on relationships with family and friends arising from foster parenting. For some in McHugh’s (2007) study, this included isolation from friends and family, with older carers finding their friends did not want young children around when they were socialising. The behaviour of foster children also led to distancing from friends, with one foster carer describing how her lifestyle changed when she had two children with attention deficit hyperactivity disorder (ADHD): ‘I lost a lot of friends. My going out and visiting stopped because I had two difficult children that would scream, throw things, smash things’ (Indigenous foster parent, aged 35, cited in McHugh 2007, p. 199). Grandparents who were foster carers found they had less contact with their own adult children and grandchildren because of the behaviour of foster children.
Rutter (2000) noted it was likely that children in out-of-home-care, including foster care, would have emotional and behavioural difficulties arising from experiences of maltreatment, emotional deprivation, and disrupted attachments. The mental health of children in foster or kinship care in New South Wales was the subject of a prospective epidemiological study, which found that children in care were at high risk of mental health problems (Tarren-Sweeney & Hazell, 2006). Children aged between four and nine years in foster or kinship care under the guardianship of the Minister for the New South Wales Department of Community Services were included, with completed questionnaire reports for 347 of 621 eligible children being returned by their carers. Carers completed the Child Behaviour Checklist (CBCL) (Achenbach, 1991) which includes clinical sub-scales, such as ‘anxious/depressed’, ‘social problems’, ‘attention problems’, and others. Analysis showed that the children ‘were reported as having exceptionally poor mental health and social competence, relative to normative and in-care samples’ (Tarren-Sweeney & Hazell, 2006, p. 93). The children in foster care had higher rates of disturbance than those in kinship care. This difference was attributed to the protective experience for children who grew up with extended family, with this environment protecting them from developing attachment problems, and externalising problems to a lesser degree than children in foster care (Tarren-Sweeney & Hazell, 2006).

A proportion of children of parents with mental illness would also be in foster care, and some might have a mental illness. The experiences of support, and financial and other costs for the foster parents would be similar to those already described.

**Aboriginal families living with a family member with mental illness**

To understand the experiences of Aboriginal and Torres Strait Islander (ATSI) families who live with a family member with mental illness, it is essential to understand their historical and cultural history (Dudgeon, Wright, Paradies, Garvey, & Walker, 2014). Dudgeon et al. (2014) provided an introduction to ATSI history and culture before and after the arrival of the British in 1788. The ongoing effects of colonisation policies and actions can be seen in the frequency of social and emotional distress reported by Aboriginal and Torres Strait Islander people, when compared with non-ATSI people, presented below. Dudgeon et al. (2014) note that, while Indigenous Peoples share a common history, Torres Strait Islander culture is different from that of Aboriginal peoples, though the two are often conflated. The citations that follow use the terminology of the
respective authors and the following important aspects of life need to be understood for their role in the lives of Aboriginal families in contemporary Australian society. Aboriginal peoples comprise many distinct groups with separate languages, customs, and beliefs. Historically, families were connected through:

extensive systems of kinship and skin groupings which located individuals in the community and neighbouring clans within relationships of caring, sharing, obligation and reciprocity. Essentially, the kinship system provided a very secure attachment system that established caring relationships so that everyone grew up with multiple carers and attachment figures, and, in turn, provided care for others (Milroy, 2008, p. 127).

These family and kinship relationships continue to influence Aboriginal families (Milroy, 2008). While Aboriginal peoples comprise many distinct groups, they share common experiences of history, as well as connections through ancestry, spirituality, song and story lines, and ceremony (Dudgeon et al., 2014; Milroy, 2008), and these are central to their holistic view of health.

Integral to the holistic view of health held by many Indigenous Australian people is ‘social and emotional wellbeing’ (SEWB), the term preferred to ‘mental health’, as it reflects a more positive approach to health; the social, emotional, spiritual, and cultural wellbeing of the whole community is essential for the health and wellbeing of the individuals in that community:

The integrity of relationships between people and spiritual entities and the clarity of connections between people and land contribute greatly to SEWB of Indigenous people. Conversely, ruptures to significant relationships and markers of identity including access to culturally significant sites and socially significant persons can serve to compromise the quality of an individual’s or a community’s SEWB (Garvey, 2008 p. 2).

**Surveys of the social and emotional wellbeing of Aboriginal adults and children**

A survey of the social and emotional wellbeing of Indigenous people conducted in 2004-2005 (Australian Bureau of Statistics, 2006) found that people aged 18 years or older were twice as likely as their non-Indigenous counterparts to experience high or very high levels of psychological distress (Garvey, 2008). Further, the social and emotional wellbeing of
children aged between four and 17 years was surveyed in Western Australia (Zubrick et al., 2005). It was found that 26% of Indigenous children aged four to 11 years were rated by their parents as being at high risk of clinically significant emotional or behavioural difficulties, compared with 17% in the general Australian population. For Aboriginal young people aged between 12 and 17 years, 21% were at high risk of clinically significant emotional or behavioural difficulties, compared with 13% of children in the non-Aboriginal population (Zubrick et al., 2005). Children in the primary care of a person with a long-term, debilitating medical condition, or a person who had used mental health services previously, were more likely to be at high risk of clinically significant emotional or behavioural difficulties than children in the care of a healthy person who had not accessed mental health services (Zubrick et al., 2005).

**Risk and protective factors to Aboriginal social and emotional wellbeing**

Interrelated risks and cumulative effects over time impact on the social and emotional wellbeing of Aboriginal children and adults. Zubrick et al. (2014) listed the following risk factors: discrimination and racism; widespread grief and loss; child removals and unresolved trauma; life stress, such as death of a family member or close friend and striving to maintain cultural heritage while dealing with ongoing discrimination; social exclusion; economic and social disadvantage; incarceration; child removal by care and protection orders; violence; family violence; substance use; and physical health problems. Factors protecting Aboriginal social and emotional wellbeing included connection to land, culture, spirituality, and ancestry; kinship; and self-determination, community governance, and cultural continuity (Zubrick et al., 2014). These health-protecting factors were a source of resilience and compensated for the impact of stressful circumstances on social and emotional wellbeing (Zubrick et al., 2014).

**Experiences of Aboriginal families living with a family member with mental illness**

Wright (2014) explored the experiences of family members living with a relative with a mental illness and found the support provided by a family member might go unnoticed by service providers, although the kinship and family network could be very important for the person with mental illness. The experiences of Aboriginal people with a mental illness, and those caring for them, also showed how mental illness could fracture and distance some family members (Wright, 2014). One participant described the importance of her grandmother who supported her in recovery; conversely, another’s brother thought she
could just ‘snap out of it’ (Wright, 2014, p. 247). Some participants described the physical and emotional costs of caregiving for a family member, including feeling hopeless and exhausted, and having to find the strength to keep going; others described the strength gained from their Aboriginality and culture (Wright, 2014).

The children of parents with mental illness can be invisible to service providers and within families, and their needs overlooked. Joan was a grandmother, and described the focus of her family being on her son. When the police attended the home her son told his children not to open the door, the police broke down the door, and the children witnessed their father being taken involuntarily to hospital. Joan reflected on the impact of this on her grandchildren:

Yeah, you know how children are, they can take things or leave it, but some little things every now and again would come out where you think, ‘Oh goodness me’! You know, ‘Maybe the kids should have had some counselling’, so you had little talk to them and they would say ‘Nah that’s fine, Dad’s just this person, that’s just Dad’. You know … they sort of handled it really, really well (Joan, cited in Wright, 2014, p. 248).

An Aboriginal framework of caregiving acknowledges the historical, social, cultural, and political realities of the lives of Indigenous peoples. This includes the impacts of dispossession and forced removal of people from their lands, and of children from their families (Wright, 2014).

Based on his study of the lived experiences of Aboriginal people, Wright’s (2014) framework:

locates care within the family rather than a single individual, and, in turn, the family is embedded within a larger cultural community and social context. Aboriginal people understand the importance of care in providing stability and as such have prioritised caregiving in their families and communities (p. 253).

It includes four activities: ‘caring about’, ‘taking care of’, ‘providing care’, and ‘receiving care’ (Wright, 2014, p. 253). In summary, Aboriginal children and families living with, and caring for, a family member with mental illness do so in a unique historical and cultural context, which is ‘often a seamless activity involving individuals, families and communities’ (Wright, 2014, p. 252).
Conclusion

The personal, social, and economic impact of mental illness on those who have the illness is well recognised. However, there are significant gaps in information and understanding relating to those living with a family member with mental illness. In most of the groups described above, little useful data was available to determine the prevalence in each group, and research concerning impacts and needs was limited or non-existent. This lack of information and evidence means that service providers do not have access to data on the impacts on the physical and mental health and wellbeing of individuals and family groups to inform their understanding of, and services to, family members in the groups described in this chapter. Chapters 3 and 4 present the theoretical and research context for the study, further revealing the complexities of the environment, including community attitudes experienced by children and families living with a family member with mental illness.
Chapter 3

Theoretical framework

Chapter 2 discussed research concerning the various family groups affected when a family member has a mental illness, and also cited examples of family members’ lived experiences. This and the following chapter examines the theoretical frameworks used in this study to understand and explain these experiences: ecosystems theory, the theories of stigma and recognition, and social support theory. The chapter posits that ecosystems theory best explains the systems, relationships, and interactions when family dynamics adapt themselves to dealing with mental illness and the stigma it generates. It underlines the need for recognition of mental illness and its impacts at all levels of society – individual, group, organisational, social, and political. Ecosystems theory enables an understanding of how families are affected by each level of their environment, the services available to them, the communities in which they reside, work, and play, the policies undergirding and influencing service provision and community support, and the social attitudes and values that influence how mental illness is recognised and treated in society.

Given that stigma is one of the most powerful influences associated with how people living with mental illness are accepted in society, the theory of social stigma is reviewed to explain attitudes that discourage people from seeking the very assistance they need. In particular, Goffman’s (1963) theory helps explain the endemic stigmatisation of mental illness in society. He shows how individuals and families are invalidated by stigmatising practices that, in terms of Honneth’s (1995) theory of recognition, might be seen as instances of misrecognition.

Honneth’s (1995) theory of recognition helps explain social relations and the mutual influence of attitudes and behaviours that validate or invalidate people’s experience of mental illness. Honneth calls for mutual respect among individuals and groups that is frequently denied to people living with a mental illness and their families due to the stigma associated with mental disorders and the people who have them.

The theories relating to ecosystems, stigma, and recognition emphasise the importance of supportive social systems when a family member has a mental illness, and
social support is discussed in Chapter 4. Table 3.1 provides an overview of the theoretical framework used in this study.

Table 3.1: Theoretical framework

<table>
<thead>
<tr>
<th>Theories</th>
<th>Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ecosystems</strong></td>
<td>Microsystem</td>
</tr>
<tr>
<td>Family unit</td>
<td>Interconnections between settings</td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td>Individual and family experience of stigma</td>
</tr>
<tr>
<td><strong>Recognition</strong></td>
<td>Family love</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td>Support of family, friends and neighbours</td>
</tr>
</tbody>
</table>

Ecological systems – ecosystems – theory

Bronfenbrenner’s (1979, 1986) ecological systems theory – referred to in shorthand as ecosystems theory – provides insights into the interactions between the various systems affected by mental illness and is useful for the study of the family to accommodate the complex layers of the family environment, each of which affects child and family development and wellbeing. Drawing on ecology, the study of natural systems in their physical environment, Bronfenbrenner (1979) conceptualised the ecological environment of families as ‘a nested arrangement of concentric structures, each contained within the next. These structures are referred to as the micro-, meso-, exo-, and macrosystems’ (p.)
the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger context in which the settings are embedded (Bronfenbrenner, 1979, p. 21).

The ecosystems perspective has been part of the practice orientation of social work since the 1970s, proving more appealing to social workers than the ‘individualizing psychoanalytic models of intervention popular in the 1950s and 1960s’ (Ungar, 2002, p. 481). According to Greif and Lynch (1983), the ecosystems perspective did not dictate what a practitioner should do, but acted as a conceptual infrastructure that allowed for practice in the micro through to the macro systems formulated by Bronfenbrenner (1979). It was based on ecology, or the scientific study of complex reciprocal and adaptive transactions among organisms and their environments (Greif & Lynch, 1983). In the study of families, the biological processes in ecology were translated to social processes, so it was the contextual field of forces, or services in the community, and the relationship between these and the family, and the relationship between the services that constituted the ‘systems’ of ecosystems theory. Ecology did not explain why one system or set of variables had a specific impact on another, whereas General Systems Theory (GST) explained the way in which a system operated, including its internal processing and interaction with its subsystems, and with other systems (Greif & Lynch, 1983; von Bertalanffy, 1968). The present study used this ecosystems perspective to examine the experiences of support of the children and adults living with a family member with mental illness who participated in the research. It assumed that they would be influenced by, and would influence, each level of the environment, as shown in Table 3.2.
Table 3.2: Ecosystems framework related to the families in this study

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Relation to the families studied in this research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Microsystem</td>
<td>The family unit and immediate environment</td>
<td>Family living with a family member with mental illness, and degree of support available</td>
</tr>
<tr>
<td>Mesosystem</td>
<td>The interconnections between the structures of the microsystem</td>
<td>Relationships among agencies with whom the family may relate</td>
</tr>
<tr>
<td>Exosystem</td>
<td>The institutional infrastructure – policies and services, including education, health, welfare, legal, and monetary</td>
<td>Development of policy and service activity influencing the lives of families and children</td>
</tr>
<tr>
<td>Macrosystem</td>
<td>Cultural values, customs, and laws that influence community attitudes to mental illness</td>
<td>Influence on funding and service provision to families and children living with mental illness</td>
</tr>
<tr>
<td>Chronosystem</td>
<td>Relates to individual and family life cycle changes</td>
<td>Effects of health and illness on developmental changes for individuals and families</td>
</tr>
</tbody>
</table>

Based on Bronfenbrenner’s (1979) framework shown in Table 3.2, in this study:

- The **microsystem** included the agency supporting the participants at the time, other services used, such as General Practitioners, mental health clinicians and counsellors, as well as the broader systems in which they interacted, such as the school, childcare, and social and sporting clubs.
- The **mesosystem** encompassed the relationships among services, and their significant impacts on families, depending on the levels of cooperation and collaboration taking place. Where these arrangements were not working effectively, families might not be well-served.
- The **exosystem** incorporated the policies and institutions affecting the lives of families, such as government departments of health, education, and human services.
- The **macrosystem** comprised the broader sociocultural context and the attitudes and beliefs people hold about mental illness, the role of family members as carers, and the extent to which they are formally supported in this role, which, in turn, is influenced by public attitudes towards family support.
According to Wakefield (1996), the ecosystems perspective may be clinically useful in four ways: helping the clinician to identify circular causal connections between persons and environments, helping to formulate a comprehensive assessment, integrating other social work theories, and correcting clinical bias toward individualistic therapeutic interventions. It can also contribute to understanding individuals and families in different social and political environments.

Ecological systems theory highlights the mutual relational influences between the various systems that are important to individuals, children, and families (Bronfenbrenner, 1979). The broader economic, political, and social environment is seen, in turn, to influence the development of culturally appropriate competencies to sustain social support. Hence an ecological approach recognises the influence of factors beyond the family and other immediate connections (Tietjen, 1989). Thus it posits a link between structural inequalities, socioeconomic circumstances, and health factors on family functioning (Jack, 2000). These, in turn, influence access to, and the development of, social supports. Similarly, the physical – air quality, hazardous materials, and pollution – and social – school, workplace, and neighbourhood – environment are also influential (Shumaker & Brownell, 1984).

The study thus viewed stigma relating to mental illness in terms of its impacts on those with such illnesses and their families at an individual and family and organisational and institutional level. The theory of stigma informed understanding of the social policies supporting families, and the community attitudes and values that influence knowledge and awareness of the experiences of people who have mental illness. The following section discusses these factors.

Theory of stigma

In ancient Greece, a stigma was a mark tattooed onto the skin that identified the wearer as a slave or a criminal (Arboleda-Flórez, 2008; Falk, 2001). Influential sociologist of the twentieth century, Erving Goffman, defined stigma as the phenomenon whereby an individual with an undesirable attribute was deeply discredited by his or her society and marginalised as a result of this attribute. Goffman (1963) set out three ‘grossly different types’ of stigma:
First, there are the abominations of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family (Goffman, 1963, p. 14).

In terms of Honneth’s (1995) theory of recognition, discussed below, stigma may be seen as an instance of misrecognition whereby others attach negative labels to aspects of the identity of an individual or group, and exercise varieties of discrimination, which hamper their life chances (Goffman, 1963). This discrediting served the purpose of ordering the world by demarcating the stigmatised individual from others, and reinforcing a ‘fragile sense of self-identity and self-worth through the pathologisation of pariahs’ (Porter, 2002, p. 63).

Falk (2001) noted that all societies stigmatised certain conditions and behaviours and, in so doing, delineated insiders and outsiders. Hence, according to the 2001 World Health Report, stigma was ‘a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society’ (WHO, 2001a, p. 16).

The negative stereotyping perpetrated through stigmatising groups or individuals served particular functions, such as justification where stereotyping provides reasons for otherwise unjust actions committed against the stigmatised groups, and differentiation where stereotyping creates a clear distinction between the in-group and the stereotyped out-group, especially when the boundaries between them were eroding (Tajfel & Forgas, 2000). Applied to people with mental illness, stereotyping reinforces perceptions that they are dangerous, justifying their subjection to involuntary treatment. Differentiation minimises social anxiety about the effects of mental illness by labelling people so affected as requiring special treatment (Falk, 2001; Sayce, 1998).

Stigmatisation affects people’s life chances in areas such as health, housing, employment, and freedom from persecution, with social, cultural, economic and political power influencing this distribution (Link & Phelan, 2001). Link and Phelan (2001)
illustrated the conferring of stigma by one group upon another with the hypothetical example of clinicians and patients in a mental health setting. In their example, the clinicians would have the power to confer stigma on patients through the socially sanctioned power of their professional training and role. On the other hand, the patients might label a clinician a ‘pill pusher’, and apply stereotypes such as ‘cold’ and ‘arrogant’, and exchange derogatory comments, but their behaviour would not confer stigma as they did not have the power in this situation. While people subjected to stigma were generally portrayed as helpless some might be able to actively use ‘available resources to resist the stigmatising tendencies of the more powerful group … making it inappropriate to portray them as passive recipients of stigma’ (Link & Phelan, 2001, p. 378).

Link and Phelan (2001) argued that the assumption that people subjected to stigma were passive recipients was based on two main challenges to the study of stigma. The first challenge was that many social scientists who studied stigma did not belong to stigmatised groups, but studied the groups from the ‘vantage point of theories that are uninformed by the lived experience of the people they study’ (Link & Phelan, 2001, p. 365). This approach contributed to misunderstanding of the experience of those who were stigmatised and the perpetuation of unsubstantiated assumptions, for example, that the disabled person was a victim when they might not accept or assume this role, and that having a disability was synonymous with needing help and social support when not all disabled people drew on or experienced the need for public services. The second challenge was that research on stigma took an individual focus, that is, the stigma was seen as something in the person being studied (Link & Phelan, 2001). In contrast, the study of discrimination did not focus on the recipients of discrimination, but on those who did the discriminating.

Sayce (1998) stated that the issue of different conceptual models, that is stigma and discrimination, was not merely one of semantics, but that different conceptual models pointed to different understandings of where responsibility lay for the ‘problem’, and different prescriptions for action. Sayce (1998) used the example of racism to highlight the difference between discrimination and stigma. Discrimination arising from racist ideas and actions can be challenged through media, legislation, and education. On the other hand, if the problem were constructed as relating to the stigma of being black, for example, the focus would be on the individual, with the solution being to encourage the person so stigmatised to have higher self-regard or stop feeling inferior or insecure (Sayce, 1998).


Stigma related to mental illness

As Goffman (1963) noted, attitudes, and values change over time as new knowledge and understanding emanates from the social events occurring at any particular moment. He showed how social stigma relating to people with mental illness, and their families by association, has changed over time through the actions of institutions at the exosystem level, such as community education programs about mental health initiated by government departments, as well as the influence of high profile individuals who have a mental illness, and the actions of mental health consumers themselves. The stigmatisation of mental illness has long led to superstition, punitive treatment and marginalisation of mentally ill people, and stigma has ‘always been attached to mental illness, whatever its supposed cause’ (Falk, 2001, p. 42). Early Greek and Hebrew sources assigned conduct now known as ‘mental illness’ to demonic possession, such was the nature of knowledge in ancient times (Falk, 2001). Up until the seventeenth century, the mentally ill were seen as agents of Satan, or referred to as witches, who were tortured, or exorcised (Zilboorg, 1941). Even today, some regard mental disorders as a sign of weakness. The mentally ill are perceived as dangerous and a safety risk, in need of social control, or to be kept at a distance socially. There is no wonder then that people who are mentally ill are reluctant to disclose this to others (Jorm & Oh, 2009). These forms of stigma are ‘fuelled by societal attitudes and practices, discriminatory policies, tendencies toward concealment and silence, and structural processes that preclude the seeking or funding of adequate treatment’ (Stier & Hinshaw, 2007, p. 109). Due to stigma and discrimination towards those with mental illness, people are being denied the right to function as full citizens, and to participate actively in the community as workers, parents, and community members (Sayce, 2000).

Internalised or self-stigma

Stigma operates through discriminatory behaviour of others towards people with mental illness, but may operate through the individual through socialisation, leading people to apply negative stereotypes to themselves. This leads to diminished self-esteem, self-efficacy, and self-confidence, and fears of rejection (Corrigan, 2004). They ‘internalize stigmatizing ideas that are widely endorsed within society and believe that they are less valued because of their psychiatric disorder’ (Corrigan, 2004, p. 618). Self-stigmatising experiences of mental health consumers have been documented in first-person accounts in the literature, showing how these experiences lead mental health consumers to isolate
themselves and withdraw completely from social interaction, thus perpetuating the cycle of stigma (Angell, Cooke, & Kovac, 2005).

In spite of the negative influences and portrayals, some people with mental illness remain indifferent to stigma, or respond with a sense of empowerment (Crocker & Major, 1989; Rüs'ch, Lieb, Bohus, & Corrigan, 2006). In a study of 90 women with borderline personality disorder (n=60) or social phobia (n=30), Rüs'ch et al. (2006) found that high self-esteem and a sense of empowerment was associated with a low level of perceived discrimination, and low perceived legitimacy of discrimination, with no difference between the two diagnostic groups. The women with borderline personality disorder recorded higher group identification than the women with social phobia, although group identification did not relate to higher self-esteem and empowerment (Rüs'ch et al., 2006). This difference in group identification was in contrast to other stigmatised minority groups, such as gay men, who experienced a protective in-group bias (Frable, Wortman, & Joseph, 1997).

**Stigma and attitudes to mental illness**

This section examines the research on attitudes towards people with mental illness as follows:

- Community attitudes towards people with mental illness
- Attitudes of children toward people with mental illness
- Attitudes of mental health professionals toward people with mental illness
- Attitudes of professionals towards parents of children with mental and emotional disabilities

**Community attitudes**

Angermeyer and Dietrich (2006) reviewed 52 population studies, published between 1990 and 2004 and conducted in 24 countries on all continents, at a national, regional or local level. Most used personal interviewing of a random sample of participants to examine public beliefs about and attitudes towards people with mental illness. They found that misconceptions about mental illness prevailed and a substantial number of respondents could not recognise specific mental disorders, and considered people with mental illness as dangerous, unpredictable, and fearsome, although the majority considered them to be
in need of help. There was a tendency for negative attitudes to be positively associated with age and negatively associated with education. The acceptance of people with mental illness was positively associated with familiarity with mental disorders (Angermeyer & Dietrich, 2006). In a subsequent Australian study, Abbu and Nelson (2008) conducted telephone interviews with 600 people aged 18 years and over using a fixed response method. While most respondents (68%) were positive about working with a person with mental illness, only 29% would trust someone with a mental illness in a position of high responsibility. A minority of respondents (34%) would be comfortable with their child sharing a flat with someone with a mental illness, and only 36% expressed confidence in the parenting abilities of people with mental illness.

**Attitudes of children**

Children and young people have participated in studies examining their knowledge and attitudes towards people with a mental illness, their attitudes towards peers who have a mental illness, and the factors which have influenced their attitudes. Young children who participated in studies conducted by Wahl (2002) and Weiss (1986) did not have clear knowledge of what mental illness was, but children as young as five years displayed negative attitudes toward mental illness. Adler and Wahl (1998) found that, in spite of their lack of understanding, children seemed to know that mental illness was undesirable and this did not seem to change over time. They continued to regard people with mental illness as people to fear, distrust, and dislike.

Walker, Coleman, Lee, et al. (2008) studied the attitudes of children and young people towards peers with a mental illness. They administered surveys to 1318 children and adolescents representative of the four predominant ethnic groups in the USA, white people, African Americans, Asian or Pacific Islanders, and Hispanics or Latinos. Participants were randomly assigned to one of three conditions in which they were presented with a vignette of a peer with Attention Deficit Hyperactivity Disorder (ADHD), depression, or asthma. They responded to 18 items across four scales: negative and positive attributes, social distance, and family attitudes. The mean scores for ADHD and depression were significantly higher than those for asthma, with depression eliciting the most negative stigmatising responses.
Factors which influenced the attitudes of 415 high school students towards people with mental illness were found to include their association with people with mental illness, such as a family member, or personal experience of mental illness, and the attitudes held by their parents (Watson, Miller, & Lyons, 2005). Familiarity with mental illness was associated with a more positive attitude, but Watson et al. (2005) recommended that strategies aimed at reducing stigma be designed to reduce ‘categorical’ thinking in young people, such as ‘they are easy to spot’, or ‘their life is pretty much over’ (p. 772).

An Australian study of young people aged between 12 and 25 years found that exposure to mental disorders and help-seeking in oneself or another was associated with lower scores on some components of stigma but not on others (Jorm & Wright, 2008). For example, only the personal history (of mental illness) predictor variable increased the perception of negative attitudes from others, while only the predictor variable of contact (with mental illness) through family and friends decreased reluctance to disclose having a mental illness (Jorm & Wright, 2008).

**Attitudes of professionals**

The attitudes of mental health professionals towards people with mental illness could be assumed to be more positive than those of the community in general, but this is not so, as reported by an Australian study which surveyed the experiences of people with mental illness, and other studies reporting the findings of attitude surveys. Attitudes of mental health professionals have been studied alone, and alongside broader community attitudes. The Mental Health Council of Australia (2011) conducted a survey of mental health consumers and carers to examine their experience of the attitudes of mental health and other health professionals. Across all diagnostic mental health categories, 29% of consumers reported being subjected to stigmatising attitudes by treating health professionals. This increased to 54% for consumers with post-traumatic stress disorder, and 57% for those with borderline personality disorder (Mental Health Council of Australia, 2011). A review of studies comparing the attitudes of professionals towards mental illness with those of the community reported that, in most studies, the beliefs of the mental health professionals did not differ from those of the general public (Schulze, 2007). While mental health professionals had more positive attitudes towards psychiatric treatment and patients’ civil rights, their attitudes concerning stereotypes and social distance were generally negative (Schulze, 2007). Another review of studies of the
attitudes of mental health professionals, conducted in the five-year period to 2009, found that they appeared to have positive attitudes towards the mentally ill (Wahl & Aroesty-Cohen, 2009). However, within the positive findings, negative attitudes emerged: the mental health professionals shared the community view that people with mental illness were dangerous, they doubted the possibility of recovery, and believed people with mental illness should not marry and have children (Wahl & Aroesty-Cohen, 2009).

The attitudes of professionals delivering services to children and young people could negatively impact on their parents and carers, although variations might occur between countries. A cross-disciplinary comparison of professionals (child psychiatrists, psychologists, and social workers) in mental health services in the USA found that parent-friendly beliefs and attitudes were strongly associated with familiarity with parent support groups and information sharing (Johnson & Renaud, 1997). Respondents endorsing a neuropsychological (the relationship between the nervous system and cognitive functioning) orientation (child psychiatrists) were less blaming of parents and more supportive of the use of medication, while those endorsing ego psychological and family systems approaches (social workers) tended to blame parents and devalue information sharing. Psychologists took a position midway between these two groups. This study was replicated with Australian social workers (Ainsworth & Hansen, 2000), who were accessed through the professional organisation (Australian Association of Social Workers), and completed the same survey measure (Provider’s Beliefs About Parents, PBAP) developed by Johnson, Cournoyer, and Fisher (1994) and used by Johnson and Renaud (1997). The study conducted by Ainsworth and Hansen (2000) found that 61.9% of Australian respondents ‘either agreed or strongly agreed with items that reflect a parent blaming position’ (p. 41), although the five-factor solution reported by Johnson and Renaud (1997) (blame, inform, validate, medicate, and instruct) was not replicated. This finding means that results of the US study have limited standing in relation to the attitudes of Australian social workers, with Ainsworth and Hansen (2000) cautioning social workers ‘to carefully check measurement instruments developed elsewhere before using them in Australian studies’ (p. 42).
Impact of stigma related to mental illness on families, parents, and children

The negative attitudes of others about people with mental illness flow on to those who love, live, and care for them. The impact of stigma on families, parents, and children may influence them as families through feeling embarrassment and shame, as parents through loss of confidence and avoiding help seeking, and as individuals through loss of self-esteem and isolation from friends and the community. This section examines the impact of stigma on:

- Families
- Parents who have a mental illness
- Children and young people who have a parent with mental illness

Impact of stigma on families

People with mental disorders in any country and culture experience stigma which serves as a barrier to social inclusion, and prevents access to services and treatment (Ademac, 1996; Phelan, Bromet, & Link, 1998; Tsang, Tam & Cheung, 2003; WHO, 2001b); by association it could also ‘be said with certainty that the families of the mentally ill are … the victims of the stigma that attaches to the mentally ill themselves’ (Falk, 2001, p. 52). Goffman (1963) described this as ‘courtesy stigma’. With the introduction of deinstitutionalisation in Australia from the early 1990s, families became directly involved in the care of the person with mental illness (Gerrand, 2005). Thereafter, the privacy, or secrecy, afforded in earlier times by the admission of the ill person to an institution was no longer available (Porter, 2002).

Prior to deinstitutionalisation, blame for mental illness was frequently attributed to faulty parenting and dysfunctional family dynamics (Stier & Hinshaw, 2007). This led to individuals and their families feeling guilty and embarrassed at the existence of mental illness in the family, and anxiety that they might face discrimination and prejudice from extended family members, friends, and community members if this were known (Wahl, 1999). There were few resources available at the time to help a person with mental illness, let alone their families, and from this evolved the self-help movements for families caring for a family member with mental illness (Snowdon, 1980).
The experience of intense anxiety, embarrassment, and fear of discrimination relating to a family member with mental illness was reported 60 years ago, following a study of 33 families. The female participants were the wives of first-admission psychiatric patients, and reported experiencing high levels of anxiety concerning attitudes of others towards the mental illness of their husbands (Yarrow, Clausen, & Robbins, 1955). One wife described herself as living ‘in horror – a perfect horror – that some people will make a crack about it to Jim’, her child, ‘and suppose after George gets out everything is going well and somebody throws it up in his face. That would ruin everything. I live in terror of that – a complete terror of that’ (p. 34). Further findings from this study were the wives’ fears of social discrimination, including their husband’s job being endangered, worries at being avoided by friends, and that their children would be excluded or taunted by other children because of their father’s illness (Yarrow et al., 1955). These impacts of stigma remain evident in studies conducted over the next 50 years, and in first-person accounts.

Thirty years after the study by Yarrow et al. (1955), a study of 487 members of a mental health self-help organisation NAMI (National Alliance for the Mentally Ill) in the United States sought participants’ views of stigma (Wahl & Harman, 1989). The study found that most frequently cited effects on families were lowered self-esteem and damaged family relationships, with 22% of respondents reporting that stigma had an unfavourable impact on their relationship with other family members, 21% saying it had an unfavourable impact on their self-esteem, and 20% saying it had an unfavourable impact on their relationship with their mentally ill relative. Mental health professionals were generally considered as not contributing to stigma, although 20% of respondents indicated that talking with a mental health professional was not helpful in dealing with stigma (Wahl & Harman, 1989). The most helpful aid identified (86%) was factual information about mental illness (Wahl & Harman, 1989), which was confirmed in an Australian study of consumers and workers by Darlington and Bland (1999). Wahl and Harman (1989) also found that 78% of respondents found that interaction with other families having a relative with mental illness was very helpful. These findings supported the central functions of NAMI, which aimed to provide information and to link families. The self-help movement for families having a family member with mental illness evolved from the lack of resources and supports available following the process of deinstitutionalisation (Wahl, 1999).

A review of 12 family stigma research studies found that family members and relatives were negatively affected in various ways by prejudiced and discriminatory
attitudes of others towards their mentally ill family member (Larson & Corrigan, 2008). For example, families might avoid social situations, spend energy and resources on hiding the secret, and experience discrimination within employment and or housing situations (Larson & Corrigan, 2008). Larson and Corrigan (2008) found that in just over half of the studies ‘between quarter and a half of family members believed they should hide their relationship with a family member with mental illness in order to avoid bringing shame to the family’ (p. 88).

In a further three studies of family experiences, between 20% and 30% of family members reported having lower self-esteem because they had a relative with a mental illness (Larson & Corrigan, 2008). When parents were blamed for the onset of mental illness or for not helping the unwell person to adhere to recommended treatments, sympathy for the family decreased, and help for the family was withheld (Larson & Corrigan, 2008).

Other possible impacts of mental illness stigma on family members may be on the individual, or the family or friendship group. Negative effects may impact on the physical and mental wellbeing of a family member, imposed by their caregiving role, and through the attitudes of others towards their ill relative (Corrigan & Miller, 2004). Ties across family and friendship groups may be weakened by discriminatory behaviour, through having to decide what to say to others about a friend or relative’s ‘problem’, and through sharing their experience of poverty or social isolation (Sayce, 2000).

**Impact of stigma on parents who have a mental illness**

The impact of stigma on parents with children in their care (or possibly cared for by others) was influenced by attitudes held towards people with a mental illness in general, with one study finding that attitudes towards parents were likely to be harsher because children were involved (Abbu & Nelson, 2008). The impact of stigma on parents might include shame and discrimination: shame at having a mental illness, and shame at the effect on daily functioning as a person and a parent, and discrimination in accessing employment and private housing (Kelly, 1999).

A study of 40 parents in the UK found that when parents have a mental illness ‘they have to contend with a crossfire of discrimination and misunderstanding’ (Aldridge & Becker, 2003, p. 111). The study found that assumptions that a parent would not be
competent as a parent were made, based on prejudice and misconceptions, leading to the whole family becoming stigmatised (Aldridge & Becker, 2003).

The judgements made by legal and welfare professionals about parental competency might occur alongside the parent’s fight to retain their role and rights as parents to raise their children, which can exacerbate the effects of mental illness (Fox, 1999). In her first-person account, Fox (1999) described the pressure she experienced from professionals and family members to give up custody of her children: ‘I wanted to keep my family together and was devastated by the loss, but people saw my despair as part of the illness’ (p. 193). She felt that no-one thought it was possible for her to look after her family while coping with bipolar disorder, and believed she was a hopeless case. Further, no effort was made to support her in caring for her children: ‘Either I had the children and was totally responsible for their care, or I didn’t have them’. No effort was made to develop a plan to help her ‘to negotiate the demands of my mental illness and motherhood’ (Fox, 1999, p. 193).

A further impact of stigma on parents is the effect it might have on seeking help, and involvement in the community. Stigma might affect a parent’s willingness to access help and support, and engage in treatment, and they ‘too rarely seek assistance because we fear society’s last resort – the removal of our children’ (Kelly, 1999, p. 61). Parents and their children might become isolated for other reasons, as reported by Ackerson (2003), where a child’s experience of harassment and verbal abuse at school led to the child and her mother becoming reclusive.

Exploratory studies conducted with parents with a mental illness have also reported the impact of stigma: fear of their children being taken from them (see Kelly, 1999, above), as well as fears about being re-hospitalised, avoidance of them and their children by others (Bassett et al., 1999), and being seen as inadequate because their children, out of necessity, were being cared for by others (Diaz-Caneja & Johnson, 2004).

In the studies cited parenting was a significant and valued role, and parents worked to find a balance between this role, and their role as an individual. It was important to them that both roles, being a person and being a parent, were respected by professionals (Wagstaff, 2010), and they have described the apparent lack of understanding of this importance to them by mental health professionals. In the study of parents with mental illness conducted by Aldridge and Becker (2003), the parents reported that mental health
professionals discriminated between their mental illness and their parenting. While the professionals demonstrated awareness and understanding about parents’ *mental health* conditions, and made constructive suggestions in relation to treatment, they were less helpful to parents in relation to the implications of their mental illness for their *parenting role* (Aldridge & Becker, 2003). The professionals did not effectively grasp the impact of parenting on the parent’s mental illness, or the impact of their mental illness on parenting.

**Impact of stigma on children and young people who have a parent with mental illness**

The impact on a child is illustrated by an account of a boy named Will:

> Will kept his mother’s trouble secret … And he learned how to conceal himself too, how not to attract attention from the neighbours … What Will feared more than anything was that the authorities would find out about [his mother] and take her away and put him in a home among strangers  (Pullman, 1997, pp. 8‒11).

The stigma of mental illness might affect children and young people in different ways, such as awareness of their family being regarded as ‘different’ by others and having direct experiences of bullying or mocking by peers, and they might distance themselves from peers, and perceive themselves negatively because of their parent’s mental illness. Children might, or might not know about their parent’s illness. A study of 20 Norwegian children aged between eight and 22 years (they were defined by the authors as children because of their relationship to their parent) found that some of the children had been informed about their parent’s illness by the parents themselves, while others slowly realised over several years that their parents were different. The majority of the children (75%) felt embarrassment, shame, guilt, or fear, although some did not have any information about their parent’s illness (Fjone, Ytterhus & Almvik, 2009).

Children might be acutely aware of stigma, and feel ashamed, believing that their parent’s mental illness should be hidden (Somers, 2007). In a literature review of the experiences of children of parents with mental illness Gladstone et al. (2011) noted that children had observed the ‘real’ problem was the reactions of other people to their parent’s mental illness. Children knew that neighbours, relatives, and others perceived their families as abnormal, particularly when parental behaviours instigated stigmatising attitudes (Östman, 2008).
Children might experience stigma directly through negative behaviour of peers at school, and in the community, because their parent had a mental illness: ‘I used to get picked on … Sometimes like they start saying “Look at your mum she’s got bad problems and she…” stuff I can’t repeat, it gets me really upset’ (Leilah, 11, cited in Aldridge & Becker, 2003, p. 81). Aldridge and Becker (2003) found that the discriminatory experiences of children were common and ongoing, with the young person having the role of carer for their parent contributing further to judgements about them, by peers, and by professionals who assumed they were at risk due to their parent’s diagnosis.

The stigma of parental mental illness impacted on children by isolating and excluding them from supports and services, in turn perpetuating their negative experiences. They kept quiet about their parent’s illness to avoid negative comments of others, felt they could not trust or talk to anyone, and would steer away from social activities, which reduced their opportunities for normal social development. This could be children not wanting their parents to come to the school (Fjone, et al., 2009), not taking friends home, or an inability to include social activity in their daily routine (Aldridge & Becker, 2003; Hayes, 2008; Kelly, 1999).

While children might experience shame because of their parent’s diagnosis or behaviour, shame might also come from the knowledge that community attitudes stigmatised people with a mental illness. One young person described her struggle to avoid being contaminated by the stigma of mental illness:

I did not want to be identified with mom’s illness, I admit that’s the situation … The shame comes from structures in society and from those mechanisms that come into force, even if you are (cognitively) not ashamed yourself (Girl, 22, 2006, retrospective thoughts from when she was about 12-14) (Fjone et al., 2009, p. 466).

The struggle of this young person to avoid being identified with her mother’s illness is highlighted when considered alongside a study which hypothesised that genetic attributions would predict associative stigma. The exploratory study of 202 university students and community members used a vignette describing a 14-year-old girl in two situations, having a mother with either depression or schizophrenia, to examine the hypothesis that stigma experienced by the girl could be predicted by the mental illness of her parent (Koschade & Lynd-Stevenson, 2011). The study data supported this hypothesis, and a second hypothesis that participants believed the girl would develop the same disorder.
as her parent. Koschade and Lynd-Stevenson (2011) suggested their findings provided important information to school teachers and counsellors, and others aware of a child with a parent with a mental illness, in order to provide support, if the young person wanted this (Fudge & Mason, 2004). An alternative to individual support was a classroom-based approach so that all children gained an understanding of mental illnesses (Joyce, Allchin, Malmborg, Candy, & Cowling, 2003).

An adult who grew up with a parent with a mental illness has written about her memories and experiences at school, and recalled that school playgrounds were ‘places where children learn a lot about stereotypes, particularly in relation to mental illness. I recall names such as “psycho”, “nuts”, “mental”, “Dr. Jeckle and Mr. Hyde”, being freely used in the playground’ (Crowhurst, 1999, p. 183). Crowhurst (1999) was confused and hurt by this name calling, and stated that teachers should be aware that pejorative terms reinforced stereotypes and perceptions that mental illness was to be laughed at on the one hand, and on the other hand not spoken about by the child who lived with a parent affected by mental illness. The effect on the child was that it stopped a child who might need help and support from approaching an adult or friend for that help. Some teachers at the school knew about Kate Crowhurst’s home situation, but offered little support. It was not until she was in Year 12 that Kate confided in a teacher, seeking special consideration. She commented that she was a ‘perfect child’ at school and home, tried hard and did well, and deliberately worked at this, doing all she could not to draw attention to herself, or trying to be invisible (Fjone, et al., 2009). Contributing to this was the secrecy surrounding her mother’s mental illness, and Kate’s childish belief that if she was very good, she could help control her mother’s illness (Crowhurst, 1999).

Role of mental health consumers and carers in combating stigma

Sayce (2000) has noted that mental health consumers and carers were active in formal and informal advocacy to government and service providers, addressing conferences, contributing to professional development and acting as peer leaders to others experiencing mental illness, or those living with a family member who had a mental illness. The people who participated in these advocacy processes were motivated by a need to see the rights of people with mental illness acknowledged and included in the institutions and services providing for their treatment and care. An example cited of an Australian organisation working to combat stigma related to mental illness was SANE, which presented
information sessions about mental illness, in response to invitations from groups and organisations (Arboleda-Flórez, 2008). The sessions aimed to inform, and to reduce the use of pejorative language, such as ‘psycho’, or ‘schizo’, and the misplaced use of words like schizophrenia, such as, ‘the weather has been schizophrenic’, which perpetuated the myth of people with schizophrenia having a split personality.

One of the effects of stigma surrounding mental illness was that individuals and their families might feel marginalised and isolated, and not access the social support that research has shown makes a positive contribution to health and wellbeing, as discussed in the following chapter.

**Theory of recognition**

‘Recognition’ is ‘the axial principle in human relations’ and has a long philosophical pedigree with the works of Hobbes, Rousseau, Kant and Fichte acknowledging the need for respect and honour in life (Houston, 2010, p. 845). Hegel was the first theorist to give ‘recognition’ a place in social life (Houston, 2010), developing a model of the struggle for recognition (Anderson, 1995). Recognition ‘is not just a courtesy we owe people. It is a vital human need’ (Taylor, 1992, p. 26), and ‘an ideal reciprocal relation between subjects in which each sees the other as its equal … one becomes an individual only in virtue of recognising and being recognised by, another subject’ (Fraser, 2003, p. 10). It is a theory of value that maintains that respect and understanding should be at the forefront of people’s relationships with others (Houston & Dolan, 2008).

Axel Honneth (1995) reconstructed a systematic social theory of recognition through his development of the ideas of Habermas (1984, 1987), Hegel (1977), and Mead (1962). Hegel’s early thinking focused on recognition as a social phenomenon involving concrete relations between actors, while later writings took a ‘metaphysical, speculative turn’, seeing recognition as an abstract idea shaping historical events. Honneth’s (1995) view of this theoretical focus was that it led ‘away from real-life experiences of humiliation, disrespect, love and the ethical life’ (Houston & Dolan, 2008, p. 459). Honneth (1995) took up Hegel’s early work to develop his own ideas, in particular making a connection with the work of social anthropologist G. H. Mead and his theory of symbolic interactionism. In this theory, personality and environment were defined as mutually developing and interacting, such that we define ourselves through the attitudes of and
behaviours of others toward us, and ultimately from the standards of the society; language is the medium through which this interaction occurs; and shared understandings of cultural norms and rules must be negotiated continually in order for interactions to proceed coherently (Hugman, 2005). Honneth’s debt to Habermas was ‘for the insight that a communicational model of human relations was a primary means of forging human emancipation’ (Houston, 2009, p. 1282) but he believed that social criticism needed to acknowledge the primacy of human recognition in social life.

Following his study of Hegel’s early works, in particular his *System of Ethical Life* (Hegel, 1802-03/1979), Honneth (1995) extended Hegel’s theory to distinguish three forms of recognition, set out in Figure 3.1:

1. *Love* as formed in the family or primary relationships of positive regard.
2. *Social support* as the product of legal relations founded on individual rights to care.
3. *Social solidarity* or social interactions which lead to relations of qualitative recognition among the members of a society.

Honneth (1995) proposed that self-realisation depended on these three types of recognition from significant others, though they differed on the ‘how’ and ‘what’ of practical confirmation:

… in the affective relationship of recognition found in the family, human individuals are recognised as concrete creatures of need; in the cognitive-formal relationship of recognition found in law, they are recognised as abstract legal persons; and finally, in the emotionally enlightened relationship of recognition found in the State, they are recognised as concrete universals, that is, as subjects who are socialised in their particularity (p. 25).
Figure 3.1: Honneth’s (1995) schema of Hegel’s stage theory of recognition

<table>
<thead>
<tr>
<th>Object of recognition</th>
<th>Individual (concrete needs)</th>
<th>Person (formal autonomy)</th>
<th>Subject (individual particularity)</th>
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<tr>
<td><strong>Mode of recognition</strong></td>
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<tr>
<td>Intuition (affective)</td>
<td>Family (love)</td>
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<td>Concept (cognitive)</td>
<td>Civil society (law)</td>
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<tr>
<td>Intellectual intuition</td>
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<td>State (solidarity)</td>
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<tr>
<td>(affect that has become rational)</td>
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</tbody>
</table>


Honneth (1995) believed that the division of social life into three spheres of interaction, while plausible, demonstrated this division of social life and required validation. Honneth argued that while it was ‘natural to distinguish forms of social integration according to whether they occur via emotional bonds, the granting of rights, or a shared orientation to values’ (Honneth, 1995, p. 94), it was necessary to make fruitful connections between love, rights, and solidarity, and the results of scientific research. Honneth considered that, by testing the conception that different patterns of mutual recognition correspond to a particular potential for moral development and to distinct types of individual relations-to-self scientifically, it could be:

seen whether the three patterns of relationship can … be distinguished in such a way that they form independent types with regard to (a) the medium of recognition, (b) the form of the relationship-to-self made possible, and (c) the potential for moral development (Honneth 1995, p. 95).
Honneth (1995) found empirical support for love as a form of recognition in the psychoanalytic literature, especially in the work of Winnicott (1965) and Benjamin (1988). Honneth cited Winnicott’s (1965) studies of the interactional processes between infant and mother, and the maturational processes for infants of differentiating themselves as independent entities, which ‘could only be accomplished collectively, through the intersubjective interplay of the ‘mother and child’ (Honneth, 1995, p. 98). This differentiation is a ‘struggle’ for infant and mother, with the infant learning that she is dependent on the care of an independently existing person, and the mother learning to accept the independence of her child (Benjamin, 1988; Honneth, 1995).

In contrast to love, there is little empirical support for legal relations as a form of recognition (Honneth 1995). However, conclusions might be drawn from the experiences of groups whose rights to recognition have been withheld, such as childcare workers, who were mostly women, often from minority groups, whose work is frequently devalued (Morrison, 2010).

The third form of recognition is solidarity. Honneth (1995) substantiated solidarity as a form of recognition that resulted in self-esteem in a context in which each member of a society was in a position to esteem himself or herself. Relationships in which individuals ‘esteemed’ or validated one another indicated the existence of values that allowed abilities and traits of the other to appear significant and could be said to be cases of ‘solidarity’ (Honneth, 1995, p. 129).

Table 3.3 below presents Honneth’s (1995) development of a schema from the ideas of Hegel, Mead, and Habermas, and his conceptualisation of the relationships between each form of recognition, the relationship to personality, and the consequences of disrespect for personality.

**Application of the theory of recognition framework**

Cortis (2007a) and Houston and Dolan (2008) have applied Honneth’s (1995) framework to elucidating a discussion of service-users’ assessment of a family support program (Cortis, 2007a), and to invigorate theories of social support (Houston & Dolan, 2008).
Table 3.3: The structure of relations of recognition

<table>
<thead>
<tr>
<th>Mode of recognition</th>
<th>Emotional</th>
<th>Cognitive</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality dimension</td>
<td>Needs and emotions</td>
<td>Moral responsibility</td>
<td>Traits and abilities</td>
</tr>
<tr>
<td>Forms of recognition</td>
<td>Primary relationships: Love and friendship</td>
<td>Legal relations: Rights</td>
<td>Community of value: Solidarity</td>
</tr>
<tr>
<td>Developmental potential</td>
<td>Generalisation and deormalisation</td>
<td>Individualisation and equalisation</td>
<td></td>
</tr>
<tr>
<td>Practical relation-to-self</td>
<td>Self-confidence</td>
<td>Self-respect</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>Forms of disrespect</td>
<td>Abuse and rape</td>
<td>Denial of rights and exclusion</td>
<td>Denigration and insult</td>
</tr>
<tr>
<td>Threatened component of personality</td>
<td>Physical integrity</td>
<td>Social integrity</td>
<td>Honour and dignity</td>
</tr>
</tbody>
</table>


Cortis’ (2007a) Australian study applied the theory of recognition to interpret how 66 users of parenting education and support groups at four family services assessed the value of family support. The service users participated in focus groups and interviews to share their experiences of receiving help in confronting complex social problems, and their aspirations for personal and social change. In summary, the participants used family support to ‘reduce domestic conflict and violence, to strengthen parent-child relationships, and to improve their confidence and connections with others’, with the outcomes described by the users reflecting ‘their visions of the purpose of community services in building a type of “social justice” they would feel each day in their families and communities’ (Cortis, 2007a, p. 254).

Cortis (2007a) stated that to meaningfully capture parents’ experiences of family support, a theoretical framework that addressed more than an insider/outside, or inclusion/exclusion, status was needed. Embodied in the participants’ responses were their aspirations for ‘self-realisation, relationship and care’ (Cortis, 2007a, p. 255), to which the modes of love, legal status, and solidarity (Honneth, 1995) gave voice.
Analysis of service-users’ responses concerning *love* revealed parents’ self-love, or self-confidence, and the mutually dependent *family love*. Self-love was accounted for through parents’ descriptions of gaining in self-confidence through their participation in groups, regaining control, and overcoming violent partner relationships, thereby re-establishing personal authenticity and achieving self-realisation (Cortis, 2007a). These changes positively affected their relationships with their children, and family love was evident through the development of more realistic expectations of themselves as parents, such as allowing themselves ‘time-out’, and developing more effective communication skills in behaviour management, for example.

Houston and Dolan (2008) applied Honneth’s theory of recognition to theories of social support, to invigorate these theories and provide a conceptual framework for reflective practice in child and family welfare. They cited a Community Mothers Program as an example of the ‘primary relationship of positive regard’, with experienced, volunteer mothers befriending, supporting, and responding in a caring manner to other mothers in disadvantaged areas of Dublin. A ten-year evaluation showed that the families receiving the intervention, in contrast to the control group, were more likely to demonstrate benefits, such as children receiving their immunisations, children being read to on a daily basis, and children being exposed to games that enhanced their cognitive development (Houston & Dolan, 2008). The *mode* of recognition, using Honneth’s schema, through which support programs such as this operated was ‘emotional support’ (see Figure 3.2). The effect on ‘practical relation-to-self’ was enhancement of basic self-confidence or self-esteem or, in Honneth’s framework, the interaction with a primary caregiver led the children to trust their own sense of what they needed or wanted and to ask for the need to be met without fear of abandonment. The positive regard the primary caregiver received from others enabled her to foster the child’s faith in her environment (Anderson, 1995).

Honneth’s (1995) second mode of recognition, legal relations (see Table 3.3), in Cortis’ (2007a) example, was categorised as ‘strong’ legal outcomes (which related directly to the legal circumstances of children, such as custody or child protection proceedings), and ‘soft’ legal outcomes which related to users’ awareness of their rights (Cortis, 2007a). In their responses, parents had described ‘highly problematic interactions with state bureaucracies and welfare professionals around matters of child protection, custody, and domestic violence, and felt stigmatised given their identification as mothers with children at risk of abuse and neglect’ (Cortis, 2007a, p. 261). Regaining care of her
children from the state child protection authority was, for one parent, a profound outcome, evidence that she could renegotiate her rights as a parent, an example of a strong legal outcome. ‘Softer’ outcomes were more prevalent, where parents felt the family support service ‘modelled respect and treated them as equal people with legitimate interests and rights as parents’ (Cortis, 2007a, p. 262). In contrast, they reported child protection authorities as treating them ‘like numbers’: ‘we don’t get listened to … we don’t get even treated with the respect of being a parent’, and ‘they do treat you like a criminal, just because you got something wrong, or done something wrong in your life’ (Cortis, 2007a, p. 262).

In discussing the second form of recognition, legal rights, as it relates to social support for families, Houston and Dolan (2008) refer to the rights of families ‘to participate in the planning and delivery of support services’ (p. 464). Several studies have either identified partnerships with parents by family centres, or recommended this participation. Fernandez (2004) conducted a review of family centres and interviewed parents and children as service users, who provided valuable information on their needs and their perceptions of service effectiveness. Fernandez (2004) recommended that ‘dialogue with service users, including children, needs to be an important dimension of service planning’ (p. 102). Pinkerton, Dolan, and Canavan (2004) conducted a meta-analysis of research findings relating to family support in Ireland and identified partnership with parents as ‘an integral part of family support’ (p. 20). Warren-Adamson (2006) reviewed the literature on family centres in the UK over the preceding 25 years and concluded that one of the strengths of the contemporary picture in the study of these programs was the inclusion of the ‘voice of the user and their satisfaction, including those at the very margins’ (p. 178).

Cortis (2007b) has reported on the participation of service users in the development of performance indicators for a nongovernment child welfare agency. Service users commented on both the content of measuring performance, such as the sense of community, and belonging that developed among each group they were part of. They also gave their perspectives on how they believed others should measure service performance. Parents could acknowledge that statistics such as attendance records could be used to judge services, but also felt that:

evidence of quality and outcomes would be obvious to observers [who could just see that parents] ‘with time … have grown into themselves, they’ve blossomed …
and you can see them growing and changing … their facial expressions are brighter, their body language is not so rigid … you can just see the change’ (Amber, parent, cited in Cortis, 2007b, p. 406).

Parents also felt that the process for data collection should reflect and ‘foster the values of respect and justice that they had experienced … in other aspects of service delivery’ (Cortis, 2007b, p. 406).

Honneth’s (1995) third mode of recognition, solidarity, ‘captured service users’ accounts of the esteem generated through the shared values, sense of belonging and achievement found at the family centres’ (Cortis, 2007a, p. 263), with three kinds of solidarity emerging from parents’ accounts: solidarity as connection, as transcending gender roles, and as overcoming cultural and economic division. The facilitating role of services in parents’ experiences of connecting with others occurred through the group processes where friendships and social connections were created. Parents could find support, feel accepted, and experience less isolation, while ‘sharing injury or humiliation’ with those in similar situations of child protection investigations and statutory removal of their children (Cortis, 2007a, p. 264). Solidarity as ‘connection’ was reported consistently by parents, they felt less alone, and able to overcome feelings of shame.

Solidarity enabled parents to overcome restrictive gender roles, with some women, through the friendships they developed at the service, gaining a sense of ‘self’ in their relationships with men. Some of the women became less dependent on men, and felt less vulnerable to domestic violence. Men also gained a sense of solidarity through their establishment of social bonds with other men in the group in a way that was intimate, and removed traditional competitive elements from heterosexual male to male relationships (Cortis, 2007a).

Solidarity also enabled parents to overcome cultural and economic divisions as parents felt ‘included on equal terms … and were not excluded or divided on the basis of money’, unlike other playgroups they did not have to pay to attend, and felt accepted regardless of ‘what race or creed you are, what colour skin you’ve got, you know that you fit in’ (Jennifer, reported in Cortis, 2007a, p. 266). The experience of solidarity of a woman from Afghanistan emerged as an outcome in her description of there being ‘no sort of discrimination … like for example I’m Afghan, that woman is Australian or Arabic, they
help us all in the same level, they don’t sort of look at us differently or help us differently’ (Saira, reported in Cortis, 2007a, p. 267).

This third form of recognition – acknowledgement by the community or social solidarity – can be experienced through participation in social networks in school, work, and community settings (Dolan & McGrath, 2006; Dryfoos, Quinn, & Barkin, 2005; Katz, 2006). Meaningful recognition in these or other settings requires mutuality ‘such that each must recognize the value and dignity of others if the recognition that others confer upon the self is to be meaningful’ (Yar, 2003, p. 116).

**Differing approaches and perceived limitations to the theory of recognition**

Garrett (2010) was critical of Honneth’s theory of recognition. With its base in social psychology, he claimed it reduced the injustice of misrecognition to a matter of individual psychological shortcomings or failings. He favoured Fraser’s (1989) contrasting approach, grounded in ‘what she refers to as the “principle of parity of participation” and the promotion of embedded social arrangements that permit all (adult) members of society to interact with others as peers’ (Garrett, 2010, p. 1522). Fraser (1989) believed that Honneth gave too much emphasis to cultural recognition and overlooked the politics of redistribution. In turn, Honneth (2003) considered that Fraser (1989) had been inattentive to political injuries and legal injustices. Hugman (2005) summarised the Fraser-Honneth debate about recognition as follows: Fraser (2001) defined recognition as the positive response to people’s right to their place in society, while Honneth (2001) saw recognition as concerning equity of esteem through all members of society being able to participate in fair or just social relations and thus achieve self-realisation. For Fraser (1989), misrecognition was a violation of justice in which more powerful social groups forced their values on less powerful groups, which included inequalities of access to material goods, while Honneth (2001) saw misrecognition as the exclusion of people from society, which he called a ‘moral injury’ (p. 48). Hugman proposed that both perspectives were warranted in social work as ‘recognition concerns material and structural inequality as well as values’ (Hugman, 2005, p. 136), with values and identity being socially produced and sustained, but interrelated with material resources that are unequally distributed (Fraser, 2001).
In discussing the limitations of the theory of recognition, Garrett (2010) acknowledged similarities in the basic or foundational ideas of Fraser (2003), Honneth (1995), and a third contemporary recognition theorist, Taylor (1992), but considered that ‘most proponents of recognition theory … tend to lack an adequate theory of the role that the neo-liberal state fulfils (p. 1519). These theorists ‘fail to acknowledge that the state, primarily intent on maintaining patterns and processes aiding and sustaining capital accumulation, can be a substantial source of oppression and hardship in itself’ (p. 1527), thereby denying recognition and participation.

Conclusion

This chapter has presented three of the theories and research informing this study: ecosystems, stigma, and recognition. When a family living with a family member with mental illness is considered in the context of the social and environmental factors relating to these theories the likelihood for misrecognition and loss of identity is highlighted, which can be seen from the discussion in Chapter 2. However, it is important not to generalise and assume that all families in this situation ‘struggle’, as some actively claim their right to participation and recognition. And with the right social support many are able to maintain health and wellbeing. The following chapter discusses the theory and research relating to social support, the fourth component of the study’s theoretical framework.
Social support

Social organisations, both formal and informal, are essential in society, particularly in providing institutional support for families trying to cope with mental illness. In Australia, the generic term ‘family support’ is used to refer to services supporting families, including family member living with mental illness. As is discussed in Chapter 6, this was institutionalised through a specific policy, the community-based mental health program, at the time this study was conducted. Theories of social support emphasise the multidimensional nature of human experience and the systems needed to support health and wellbeing (Caplan, 1974; Cohen, 2004; Gottlieb, 1981; Vaux, 1992). This chapter reviews the literature on social support as a component of the theoretical framework guiding this study (see Table 3.1 on p. 33). The importance of social support rests on the notion that people living with mental illness are embedded in relational networks that have a significant influence on their health and wellbeing, and these social networks support them through their episodic mental health conditions. The strength and quality of these social support networks is thus pivotal to their social functioning. This relational network forms the ecological context of social support, described in Chapter 3. The concept of social support became immensely popular in the field of mental health research in the 1970s and 1980s as it offered empirical and conceptual simplification, and thus appealed to policy makers (Veiel & Baumann, 1992). Shumaker and Brownell (1984) described the 1970s as an ‘era of unrestrained enthusiasm’ (p. 11) for research on, and interventions relating to, social support. The timing of this popularity coincided with the discharge of people with mental illness from large hospitals into community-based care. This was a time of immense change resulting from the policy of deinstitutionalisation (Gottlieb, 1983; Tessler & Gamache, 2000).

Defining social support

When relationships are described as ‘supportive’ the qualities this refers to are generally well understood, although the complexity of social support has made it difficult to define
(Barrera, 1986; Veiel & Baumann, 1992), and its meaning has changed over time. The term was used before the mid-1970s to denote a person, relationship, or transaction, and during the 1970s ‘underwent an insidious conceptual transformation from a concrete term to an abstract [multifaceted] construct’ (Veiel & Baumann, 1992, p. 2). Given its multidimensional nature, social support could not be easily defined (Barrera, 1986; Cohen, 1992; Laireiter & Baumann, 1992; Vaux, 1988; Walsh & Connelly, 1996). Vaux (1988) described it as a meta-concept ‘lacking specificity and definition, rather than a definable and measurable entity’ (cited in Veiel & Baumann, 1992, p. 2). Hence there are numerous definitions of social support, For example:

- Vaux (1988) saw it as a transactional process ‘between the person and his/her social network … of supportive relationships’ (p. 68) for the purpose of enhancing and complementing ‘personal resources for meeting demands and achieving goals’ (Vaux, 1992, p. 194).

- Sarason, Sarason, and Pierce (1990) saw it as primarily a cognitive or psychological characteristic of individuals.

- Veil and Baumann (1992) broke it down into four components: subjective beliefs, everyday support, potential support, and actual crisis support.

- Richman, Rosenfeld, and Hardy (1993) specified eight types of support: listening, task appreciation, task challenge, emotional support, emotional challenge, reality confirmation, tangible assistance, and personal assistance.

- Cohen, Gottlieb, and Underwood (2000) saw it as ‘the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships’ (p. 4). This is the preferred definition for the present study.

Hupcey (1998) reviewed the theoretical and empirical literature published since the mid-1970s and analysed research published between 1993 and 1996. She examined 19 studies and identified five definitional elements: type of support provided, recipients’ perceptions of support, intentions or behaviours of the provider, reciprocal support, and social networks. Cohen and Syme (1985) believed an important consideration was whether social support had been requested, accepted, and received. However, this interactional component was ‘rarely included in the theoretical definitions of the concept’ (Hupcey, 1998, p. 1232).
Hutchison (1999) observed that social support and social networks were sometimes confused in the literature, though they were different concepts. Each had varying effects on altering health outcomes and required different research methodologies. For example, social network analysis (SNA) was a research method that assessed the number and strength of social ties a person had (Granovetter, 1983).

**Theories of social support**

Early observers and researchers of human relationship and association came from one or more of the fields of anthropology, philosophy, psychoanalysis, and sociology. They theorised social support in relation to social changes arising from industrialisation (Simmel, 1903/1971), documented formal and informal groupings and networks in an island parish (Barnes, 1954), and reported observations of relationships and networks in urban families (Bott, 1955). Subsequently, epidemiologists identified an association between social support and health and wellbeing (Berkman & Syme, 1979; Cassel, 1974). This theoretical link has been explained in several ways, with stress and coping theory predominant in this research (Lakey & Orehek, 2011).

**Stress and coping theory: Support as a buffer**

Stress and coping theory has arisen among researchers who have noted the relationship between social support and human health and wellbeing. Here support is seen to have a buffering effect, protecting people from ill-health (Cohen & Wills, 1985). In his early review of research studies linking increased population density, rapid social change, and social disorganisation with enhanced susceptibility to disease, Cassel (1974) found ‘reasonably convincing evidence indicating [the role of a] lack of social supports in disease occurrence’ (p. 478). Certain marginalised groups, such as people with tuberculosis, schizophrenia, alcoholism, and those who had committed suicide, had in common a similar set of social circumstances: All had ‘been deprived of meaningful social contact’ (p. 474).

Attachment theory sees social support systems as attachments between individuals and groups of individuals that promote mastery of emotions, offer guidance, provide feedback, validate identity, and foster competence. Support eventuates when individuals help with mobilising psychological resources and mastering emotional burdens; share tasks; and provide practical, material and cognitive assistance (Caplan, 1974).
Sluzki (2010) noted human life was social from the moment of birth, while Cobb (1976) maintained support began in utero: It ‘is best recognised at the maternal breast, and is communicated in a variety of ways, but especially in the way the baby is held [supported]’ (p. 301). In this vein, attachment theorist Bowlby (1969) believed that social support was a basic human need from the beginning of life, as expressed through the bonding of infants with their mothers, and stimulation, acceptance, and affection by parents, and parent’s helpers, such as grandparents, older siblings, and other carers (Sluzki, 2010).

A stark example of the impact of a significant lack of care and nurturing on the health of infants and young children was seen in the discovery of thousands of children in orphanages in Romania after the fall of the Communist regime. A comparative study, conducted over a two-year period, of Romanian children adopted in the UK and adopted UK children, found that the severe deprivation prior to adoption suffered by the Romanian children led to attachment disturbance even when deprivation was limited to the early months of life. This suggested that early deprivation might have long-term effects on attachment behaviour and on the ability to establish relationships in later life, due to a lack of awareness of social boundaries and inability to read social cues (O’Connor & Rutter, 2000). This might affect the capacity to seek and accept support from others, and to support others later in life.

Relatedly, life-span theory suggests that developmental influences of attachment between infant and parent are the basis for expectations concerning future relationships and perceptions of support (Bowlby, 1969). A study of medical students found that participant’s initial ratings of emotional closeness to their parents was associated, at 30-year follow-up, with a greater number of close contacts in mid-life (Graves, Want, Mead, Johnson, & Klag, 1998, cited in Uchino, 2009).

**Relational theory**

Relational theory might be seen as an extension of ecological theory (discussed in Chapter 3), wherein social support is examined in relation to the multiple systems within an individual’s social network. While ecological theory examines the structure of this network, relational theory sees it as a relational entity. The theory rests on the notion that people living with mental illness are embedded in relational networks that have a
significant influence on their health and wellbeing, and these social networks support them through their episodic mental health conditions. Relatedly, social network theory examines the strengths and quality of these social support networks in terms of the strength and weakness of the ties between people (the relationships) within them (Knoke & Yang, 2008). The strength of these relational (social) networks is seen as pivotal to their social functioning. For example, Berkman and Syme (1979), in a nine-year longitudinal study, tracked 7000 adults to determine the relationship between their health and the size of, and frequency of contact with, their relational network – close friends and relatives. They found that the strength of these networks was significantly related to mortality rates, after controlling for age, initial health status, and risky health practices, such as smoking and alcohol consumption. However, their methodology did not explain how relational networks impacted on positive or negative health outcomes (Hirsch, 1981).

Several researchers have studied these relational processes (Heaney & Israel, 2008; Hinson Langford, Bowsher, Maloney, & LiIlis, 1997; Krause, 1986; Slevin et al., 1996; Taylor, 2011; Tilden & Weinert, 1987; Uchino, 2004; Wills, 1985). These researchers have examined how the exchange – giving and receiving of support – occurred in the context of relationships, and identified several forms of support being exchanged: emotional, material, informational, or relational (see Table 4.1). Of these, Hinson Langford et al. (1997) found emotional support to be the most important way of conveying feelings of being loved and cared for, esteemed, and valued.

Table 4.1: Forms of social support

<table>
<thead>
<tr>
<th>Type of support</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>Empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, caring, warmth, and nurturance are all relational qualities strongly connected to positive self-esteem and feeling valued</td>
</tr>
<tr>
<td>Tangible or material</td>
<td>Well-timed practical, financial, and material assistance provides support with problems in coping</td>
</tr>
<tr>
<td>Informational</td>
<td>Advice, guidance, and information provide help with problem solving</td>
</tr>
<tr>
<td>Relational</td>
<td>Friendship, companionship, and joint activities provide a sense of belonging</td>
</tr>
</tbody>
</table>
More recently, the giving and receiving of social support has received attention within the ethics of care literature. Some have related this to Honneth’s theory of recognition, (discussed in Chapter 3) (Fraser, 2001; Garrett, 2010). Important from an ethics of care perspective is that the recipient of the support feels supported (Gray, 2010). For example, Darlington and Miller (2000) discuss the importance of matching support to the need of the recipient, the timing and duration of the support, perceptions of support received and provided, and negative support, such as lack of reciprocity, or negative perceptions of the support by the recipient.

Relational regulation theory developed to explain the relationship between perceived support and mental health (Lakey & Orehek, 2011). It proposed that ‘perceived support and mental health are rooted in social interaction’ (p. 483) involving ordinary conversations, rather than conversations about coping with stress.

In their review, Hinson Langford et al. (1997) found several additional theories, including social comparison theory, whereby persons develop their self-concept by comparing themselves to others in their chosen group (Swann & Brown, 1990); social exchange theory which explains human behaviour as the exchange of mutually rewarding activities (Tilden & Gaylen, 1987); and social competence theory where competence is the ability to interact effectively with the environment (Pender, 1987). Finally, Vaux (1988) emphasised the ecological context within which the transactional process of social support occurred. He saw social support as a way in which people managed their social resources to meet social needs.

**Theory of social capital**

Closely related to social support is the theory of social capital, a term first used 100 years ago, and conceptualised almost 100 years before (Cullen & Whiteford, 2001; Winter, 2000). It has been defined variously as:

- The ‘features of social organisation, such as civic participation, norms of reciprocity, and trust in others that facilitate cooperation for mutual benefit’ (Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997, p. 1491).
- The ‘cultural practices, norms, networks, links, know-how and tradition through which people conduct informal interactions of all kinds … accumulated through the myriad … repeated and varied interactions, both
formal and informal’ … As such it is a ‘collective good for those communities which generate, conserve and develop it … and is freely available for the benefit of all members who take part in the community’s interactions’ (Jack & Jordan, 1999, p. 243).

- The ‘raw material for civil society … which is a “bottom up” phenomenon [originating] with people forming social connections and networks based on principles of trust, mutual reciprocity and norms of action’ (Bullen & Onyx, 2005, p. 6).

Generally, social capital theory holds that the enduring and reciprocal nature of social connection contributes to social capital in the community. Factors that erode social capital include inequalities, divisions, and exclusions, such as inequalities in wealth and power (Jack & Jordan, 1999). Jack and Jordon (1999) noted that the health and welfare of families and children had been shown to be influenced by the degree to which they were connected to their neighbourhoods.

At the individual level, relationships are pivotal to psychological and physical wellbeing. An enduring pattern of strong, ‘continuous or intermittent ties’ (Caplan, 1974, p. 7) provides a sense of belonging, as do personal relationships based on ‘equality, mutual trust and reciprocity’ (Jack, 2000, p. 714). These spontaneous relationships are seen to emerge from the needs of the individual for social contact (Caplan, 1974; Jack, 2000). Hence, fostering and strengthening informal social support systems in the community, among relatives, friends, and neighbours is seen as an effective way of enhancing people’s functioning (Jack, 2000). Caplan (1974) identified three levels within the natural or informal support system, and recognised the role of religious denominations in people’s lives (see Table 4.2).
Table 4.2: Levels within natural support systems

<table>
<thead>
<tr>
<th>Level of support</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary level of support</strong></td>
<td></td>
</tr>
<tr>
<td>Network of family and friends</td>
<td>Provide guidance, self-validation assistance with chronic problems and help in emergencies</td>
</tr>
<tr>
<td><strong>Secondary level of support</strong></td>
<td></td>
</tr>
<tr>
<td>Informal caregivers in the community</td>
<td>Provide information or assistance by people who:</td>
</tr>
<tr>
<td>• Generalists</td>
<td>• Are knowledgeable on a wide range of matters.</td>
</tr>
<tr>
<td>• Specialists</td>
<td>• Have coped with particular problems and are able to assist others since their relationships with the people they are helping have a reciprocal quality</td>
</tr>
<tr>
<td><strong>Tertiary level of support</strong></td>
<td></td>
</tr>
<tr>
<td>Formal groups and associations not directed by professionals:</td>
<td>Provide</td>
</tr>
<tr>
<td>• Generalists - voluntary</td>
<td>• Voluntary support to specific groups such as the aged</td>
</tr>
<tr>
<td>• Generalists – mutual help</td>
<td>• Mutual support to buffer times of major change, offered by groups, such as Rotary and veterans associations</td>
</tr>
<tr>
<td>• Specialists – mutual help</td>
<td>• Mutual support to manage disability or a challenging experience, such as Alcoholics Anonymous, Schizophrenia Fellowship or Mental Illness Fellowship</td>
</tr>
<tr>
<td>Religious denominations as organised support systems</td>
<td>Widely available to provide support among peers through shared values</td>
</tr>
</tbody>
</table>

Social support measures assess the perceived or actual support received from family, friends, and neighbours (Gottlieb & Bergen, 2010) in instances where support is seen as an asset in those interpersonal relationships. Social capital occurs and is accumulated through the actions of groups, neighbourhoods, and communities working together (Cox, 1995, cited in Bullen & Onyx, 2005), and is seen as a community asset.

Two studies on social capital in different communities examined the influences of neighbourhoods and the physical environment on wellbeing in two disadvantaged areas of east London (Cattell, 2001), and the social capital of three population groups in New South Wales (Bullen & Onyx, 2005). Cattell (2001) compared two micro areas of east and north-
east London, which were very deprived. Semi-structured interviews were conducted with residents about their perceptions of the neighbourhood, social networks and support, community participation, and health. The dockside history of one locality, Keir Hardie, contributed to strong community loyalties and neighbourly support networks. The housing estates of the other locality, Cathall, however, had little sense of history, the housing layout was alienating, the crime rate was high, and the high population turnover and level of antisocial behaviour made it difficult for residents to develop strong social networks. Respondents spoke of mistrust among neighbours, lack of local family support, insecurity, and fear and crime and violence, all of which were experienced as alienating. Family networks were affected as people were intimidated by the violence and reputation of the area and would not visit resident families (Cattell, 2001).

Nevertheless, self-help groups, tenant groups, and courses showed that ‘a thriving positive community … co-exist[ed] with the demoralized community’ (Cattell, 2001, p. 1505). This contrasted with the dockside locality which had a strong sense of place, with intergenerational continuity and neighbourly support being strong features. It was an insular community, where ‘you look after your own’ (Cattell, 2001, p. 1505), rather than become involved in community associations. Participants from both estates recognised the influence on health and wellbeing of their physical and social environment, and of financial and other stressors, such as bereavement. The Cathall estate was undergoing regeneration, with some of the residents observing that this was morale boosting: ‘People don’t mind going out now, and are visiting their doctors less’ (Cattell, 2001, p. 1511).

From her interview, and the literature, Cattell (2001) developed a typology of social networks for the two communities, with the networks of most members corresponding to one of the following: Socially excluded, homogeneous, traditional-heterogeneous, and solidarity. However, the networks of some residents were ‘entirely individualistic and innovative’ (p. 1506) and did not fit any of the categories.

Experiences of relationships, and of health, as reported by residents, were recognised as being interrelated, with, for example, the quality of a relationship with her husband and extended family being critical for an isolated mother with children, and having support when things go wrong, or having someone to talk to about problems also being described (Cattell, 2001). In summary, Cattell’s (2001) study demonstrated the mediating influences of intergenerational history, and the physical and social environment on social network patterns and forms of social capital created, as well as the impact of
these influences on the social exclusion of citizens, which includes ‘a reduced capacity to access social capital, and poorer health chances’ (p. 1512).

Bullen and Onyx (2005) measured the social capital of neighbourhood and community centres, and family support services, in five metropolitan and rural communities in New South Wales. They used quantitative measures to study eight elements of social capital, including participation in the local community, neighbourhood connections, connections with family and friends, work connections, proactivity in a social context, feelings of trust and safety, tolerance of diversity, and value of life. They found that social capital was not related to economic wellbeing: ‘more money and education does not necessarily mean more social capital’ (Bullen & Onyx, 2005, p. 16). However, minimal material conditions might be a prerequisite for the development of social capital: ‘people who are not able to satisfy their basic material needs find it hard to look beyond themselves’ (p. 16) and contribute to the development of social capital. The family support client group provided an example of this association, as the extent of their social capital was related to their economic wellbeing: ‘If you have extremely low levels of one, you have extremely low levels of the other’ (Bullen & Onyx, 2005, p. 16). The elements that contribute to the social capital of a community contribute to the barriers to social support, discussed later in the chapter.

Research and measurement of social support

The scope and complexity of social support has been a major obstacle to its measurement. Vaux (1992) goes so far as to say it ‘is simply not a viable theoretical construct and it cannot be measured’ (p. 194). In their contributions to clarifying the concepts related to social support, various authors have reviewed the progress of social support research and have argued for the need for conceptual clarification to facilitate consistency in research and comparability of findings (Barrera, 1986; Gottlieb & Bergen, 2010; Hupcey, 1998; Vaux, 1992; Veiel & Baumann, 1992).

Barrera (1986, cited in Gottlieb & Bergen, 2010) stated that the global concept of social support should be replaced with more precise criteria. He reviewed the structural, functional, and evaluative aspects of social support and found that, despite the diversity of definitions, the ‘concepts and their operationalisations can be organised into three broad categories: social embeddedness, perceived social support, and enacted support’ (p. 415).
Barrera (1986) defined each of these categories, and reported on the approaches investigators had used to measure them (see Table 4.3).

Vaux (1992) identified five social support constructs which, he stated, should be used to operationalise and measure each of these aspects of social support: support resources, incidents, behaviour, appraisals, and orientation. He also stated that the mode of support should be included in research, for example, support that is encouraging or informative for the recipient. The source of support should be included in social support measures to identify whether support was provided by a close confidant, or from among a wider social network (Vaux, 1992). The research should also specify whether support was being examined as a general or specific process – unique to a particular life issue, such as adaptation to chronic illness. Vaux (1992) advocated for the careful selection of research measures that specifically targeted the aspect of support most relevant to the research question, such as assessment of resources, support behaviours, emotional support, tangible support, and so on.

Veiel and Baumann (1992) agreed with the need for conceptual clarification. They proposed that social support be considered as a characteristic of the:

- Individual: This could be a stable or transient feature, such as the perception of being loved.
- Social environment, such as the supportive behaviour of others.
- Dynamic system that encompasses both the individual and the environment, such as positive gestures with great support value, or a response to support offered that has a negative effect on further support provision.

Hupcey (1998) analysed the link between social support theory and research in order to categorise definitions of social support. She argued that, due to their failure to distinguish between theoretical and operational definitions, researchers ‘have measured the variable in a simplistic manner’ (p. 1231). In her review, she found that the constructs measured remained unchanged across two time periods. The most frequent areas of enquiry were the type of support and the characteristics of the support network. Hupcey (1998) also found that in all but two studies the investigation was undertaken from the
point of view of the support recipient. Other facets of social support, such as provider-recipient interactions, were not included in the studies she reviewed.

**Table 4.3: Categories of social support and approaches to measurement**

<table>
<thead>
<tr>
<th>Category of social support</th>
<th>Approaches to measurement</th>
</tr>
</thead>
</table>
| *Social embeddedness* refers to the connections of individuals to significant others in their social environments | • Use of indicators of social ties, such as marital status and participation in the community  
• Use of social network analysis, which may involve structured procedures for identifying individuals who are important to the focal subject |
| *Perceived social support* is characterised as the cognitive appraisal of being reliably connected to others | Measures of perceived social support may include two dimensions: perceived availability of support and adequacy of supportive ties |
| *Enacted support* are actions that others perform when they render assistance to the person needing support | Measures of enacted support assess what individuals who are providing support actually do |


Gottlieb and Bergen (2010) reviewed social support concepts and measures with the aim of informing the decisions of social support researchers ‘about what to measure and how it can best be measured in … studies aimed to sensitively capture the proximal social network’s support-related functions’ (p. 511). They reviewed observational and self-reported, as well as brief and extensive measures of, support, concluding there were many checklists and rating scales that met reliability and validity requirements. They noted that support could be measured in terms of the support provided, or received, the availability and frequency of support from family and friends, and its quality, that is, the manner of its delivery – whether it had been offered in a grudging or controlling manner. Measures of support could be customised to the age group being studied, such as adolescents, adults, or older persons, or population groups, such as workers and their supervisors, parents and children, or spousal and non-spousal partners.

Gottlieb and Bergen (2010) found the majority of measures of social support had been based on self-reports gained from surveys or interviews, and that some researchers had used a daily diary. This approach was used by Walsh (2000) to enable a group of
people with mental illness to report directly on their experiences of support. Walsh (2000) prepared an assessment form that participants used as a diary. They were asked to complete daily log sheets over a four-week period. For each support incident, participants recorded the first name of the person who had provided support, the person’s relationship to the participant, and the specific action or behaviour found helpful. In analysing the responses, the support incidents were categorised as material, emotional or instrumental support, thereafter they were grouped into eight network clusters according to their relationships with the support providers, whether friends, families of origin, neighbours, or church. Walsh (2000) found that the support group categorised as informal community relations was an important source of support as this group was ‘more significant to persons with serious mental illness than to general populations’ (p. 66). Walsh (2000) noted that people with a mental illness ‘function best, and enjoy more normal lifestyles, with a workable set of informal supports’ (p. 67), and since these might be difficult for them to acquire he recommended that case managers assess client needs, and work collaboratively with them to develop informal supports.

Morrow (2001) used three methods to collect information about the subjective experiences of 101 young people aged between 12 and 15 years in the UK. To collect information about their subjective experiences of their neighbourhoods, their quality of life, the nature of their social networks, and their participation in their communities the participants were asked to write open-ended answers to questions on their social network and social support sources, their activities, their sense of belonging, and their views of friendship. Visual methods were also used, including photography and map drawing, to depict their neighbourhoods. Focus group discussions enabled them to explore their use and perceptions of their neighbourhoods. Morrow (2001) found that crucial to the sense of belonging and wellbeing of the young people were small-scale interpersonal networks based on friendship and family. The young people were also found to have limited association with formal community networks or groups, and did not have a sense of belonging to the town, but had a sense of place, knowing which areas were safe or unsafe for them.

Two Australian studies used a combination of structured self-rating scales and semi-structured interviews to assess families’ perceptions of support. Darlington and Miller (2000) interviewed 53 dual-parent families to determine which aspects of family support were most useful to families caring for young children. Families completed the
Family Support Scale (Dunst, Jenkins, & Trivette, 1984), the Family Functioning Scale (Noller, Seth-Smith, Bouma, & Schweitzer, 1992), and the Family Inventory of Resources for Management (McCubbin & Comeau, 1987), and a semi-structured interview that assessed the type, frequency, and quality of support received by the family from sources outside the family (Darlington & Miller, 2000). Findings showed that the quality of support played a greater role than its quantity leading to the conclusion: ‘the quality of support received is crucial in predicting family wellbeing and family functioning’ (Darlington & Miller, 2000, p. 74). Families who found the support they received helpful reported more open communication and democratic parenting, less conflict, and higher levels of family esteem (Darlington & Miller, 2000).

Winkworth, McArthur, Layton, Thomson, and Wilson (2010) undertook a study of 20 families with young children that were not well connected to services to determine the factors leading to a lack of connection and consequent lack of support. Families completed an adapted version of Freiberg, Homel, and Lamb’s (2007) Family Empowerment Scale and participated in semi-structured interviews on the nature and extent of their social networks. They were asked to list significant people with whom they had contact over the previous three months. Winkworth et al. (2010) found that parents regarded themselves as not well connected to services, with interconnected factors contributing to this finding. At an individual level, parents felt they lacked the informal social networks that could connect them to services: they did not know about services, and did not have friends to help them make these connections. At the provider level, parents’ accounts showed that previous experiences with formal services had left them feeling judged in relation to their parenting so they avoided actively seeking assistance again. At the neighbourhood level, parents highlighted the positive role of schools and childcare centres as sources of non-stigmatising support. Winkworth et al. (2010) noted the emphasis this placed on linking isolated families to universal services in non-judgmental ways that built trust.

**Barriers and limitations to social support**

The giving and receiving of social support takes place in the context of the physical, social, and interpersonal environment which makes it a ‘complex form of helping’ (Schilling, 1987, p. 20), influenced by barriers and limitations. Barriers to social support may be overcome through changes in individual circumstances, organisational regulations, and
attitudes and values reflected in policy and legislation. Limitations may be factors integral to, or a characteristic of, a relationship and less amenable to change.

**Barriers to social support**

Social support theory, as shown above, sees social inclusion as pivotal to health and wellbeing, especially for families living with mental illness (Quinn, Briggs, Miller, & Orellana, 2014). Conversely, social exclusion is a barrier, not only to health and wellbeing, but also to social support. Table 4.4 provides an overview of the myriad ways people may experience difficulties in accessing support from an ecosystem perspective.

**Microlevel**

At the microlevel:

- Individuals might isolate themselves through drug dependency, or deliberate attempts to avoid the authorities, through illegal activities, or fear of child removal.
- People might not want to ask for support as self-reliance is an important personal value or, with disability or age for example, people want to retain their independence.
- People might not want to be a burden on others. They might not have a family, or their family might not be nearby, or be accessible, or people might be estranged from their families, e.g., due to a family history of abuse or violence, or a breakdown in relationships (Agllias, 2011, 2013).
- They might not trust people or the authorities due, for example, to past (negative) experiences with them, such as feeling judged in some way.
- They might perceive non-supportive messages within supportive actions (reluctant support).
- Lack of reciprocity which means an exchange cannot occur (as in relational exchange theory). For example, Offer (2012) notes:
Table 4.4: Barriers to social support

<table>
<thead>
<tr>
<th>Support factors</th>
<th>Microsystem: Individual/family</th>
<th>Mesosystem: Connections between settings</th>
<th>Exosystem: Institutions</th>
<th>Macrosystem: Values, attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-isolation</td>
<td>Desire to be self-reliant and independent</td>
<td>Opportunities not taken by providers to link families to other services</td>
<td>Stringent means-tested benefits</td>
<td>Social exclusion</td>
</tr>
<tr>
<td>Not wanting to be a</td>
<td>Unavailability of family – weak ties, physical distance</td>
<td></td>
<td>Selective organisational ‘entry criteria’</td>
<td>Poverty</td>
</tr>
<tr>
<td>burden</td>
<td>Unable to reciprocate</td>
<td></td>
<td>Negative experiences of services</td>
<td>Health inequalities</td>
</tr>
<tr>
<td>Lack of trust</td>
<td>Reluctance to ask for support</td>
<td></td>
<td>Lack of knowledge of services</td>
<td>Crime</td>
</tr>
<tr>
<td>Non-supportive messages</td>
<td>included within supportive actions</td>
<td></td>
<td>Confusing information about services</td>
<td>Ageism</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ineligibility for services</td>
<td>Gender discrimination</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Long waiting lists</td>
<td>Socioeconomic status</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High staff turnover</td>
<td>Racism</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Services judge parenting</td>
<td>Cultural and language</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>differences</td>
</tr>
<tr>
<td>Life transitions</td>
<td>Life transitions – having a baby</td>
<td></td>
<td>Being out of the workforce</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death of a loved one</td>
<td></td>
<td>Having a criminal record</td>
<td></td>
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<tr>
<td></td>
<td>Moving into a nursing home</td>
<td></td>
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<tr>
<td></td>
<td>Going to jail</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal problems</td>
<td>Substance abuse</td>
<td></td>
<td>Stigma</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mental illness</td>
<td></td>
<td>Discrimination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Homelessness</td>
<td></td>
<td>Negative social attitudes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Domestic violence</td>
<td></td>
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<tr>
<td></td>
<td>Physical ill health</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical</td>
<td>Lack of transport</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>No money for bus fare</td>
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<td></td>
</tr>
</tbody>
</table>

Adapted from: Cattell, 2001; Harrison, Neufeld, & Kushner, 1995; McDonald, 2010; Schrimshaw & Siegel, 2003; Winkworth et al., 2010.
Individuals who have a limited ability to contribute to their network run the risk of being socially excluded … The most vulnerable and disadvantaged mothers, those in greatest need for support, are the least likely to have it available from their networks … [Hence their need for] support through formal channels in the community (p. 120).

**Mesolevel**

The mesosystem encompasses relationships among services, with the communication, or lack thereof, among services impacting on families. Barriers to support may arise when services and institutions miss opportunities to link families to other services that may be beneficial, e.g., when attending their general practitioner, or when visiting Centrelink for income support, or the housing department (Winkworth et al., 2010).

**Exolevel**

Organisational factors that limit access to support include:

- Stringent means-tested benefit, selective organisational ‘entry criteria’, and ineligibility for services.
- Lack of accurate knowledge of, and information about, services: parents in Winkworth et al.’s (2010) study reported confusion about information they had been given. Some did not know about the services available to them. In other instances, parents had been given information but it had not been of immediate relevance.
- Missed opportunities to link families to services that might be beneficial, e.g., through Centrelink, their doctor, or the housing department (Winkworth et al. (2010).
- Long waiting lists, high staff turnover, and lack of transport.
- Feeling intimidated by, or having previous negative experiences of, services.
- Avoidance of services: factors contributing to the parents’ avoidance of services in Winkworth et al.’s (2010) study included feelings of shame at being single parents, and being judged for their parenting style and labelled for seeking help from services; asking for help or seeking and using services signified their failure as a parent.
Cultural barriers may lead some parents from cultural and linguistically diverse backgrounds feeling ashamed to ask for help, as in their culture ‘it’s a shame to ask’ (Winkworth et al., 2010, p. 438).

**Macrolevel**

At the macrolevel, there are myriad, interrelated factors that act as a barrier to social support. These include social exclusion, poverty, health inequalities, socioeconomic status, crime, racism, ageism, gender discrimination, and disability. Differences in social support for women and men, according to Schilling (1987), are distinguished by traditional roles, with men developing ‘social supports that serve them well in the workplace’ and women tending to invest in ‘a close support network composed of family and friends’ (p. 24). Further, women are cast in the role of providers of social support and care for partners, children, and aging parents, but these groups do not, or are not in a position to, return the same amount of support to the partner, mother, and daughter (Schilling, 1987). People with disabilities may experience societal barriers which limits their network membership to others who are similarly affected, in turn further limiting their full participation in society (Schilling, 1987).

**Limitations to social support**

While social support is a fundamental necessity for human beings, being a rich and universal helping resource with positive effects for recipients, there are associated limitations (Hupcey, 1998; Schilling, 1987). Providing and receiving social support is generally defined and discussed as a positive behaviour of the provider, and a positive experience for the recipient. Social support is seen to play a significant role in protecting people from physical and mental illness, and the quality and quantity of social interactions have been identified as predictors of mental health and wellbeing. However, differing perceptions by the provider and recipient of the support, and its perceived benefits, or the lack of reciprocity in giving and receiving support, raise questions as to its value: Is it support if the recipient does not feel supported? (Hupcey, 1998; Schilling, 1987; Sluzki, 2010; Vaux, 1988). Supportive relationships are open to ‘conflict, exploitation, stress transmission, misguided attempts to help, and feelings of loss and loneliness’ (Cohen, 2004, p. 680). Many variables are related to individual needs for support, such as
dependency, locus of control, introversion-extroversion, and problem solving (Schilling, 1987).

Developmentally, social support may be positively influential through role models that parents have provided to their offspring, and in adolescence supportive networks can help young people feel accepted, but peer pressure to conform may have negative effects on educational achievement and on engaging in risk-taking behaviour such as drug use (Schilling, 1987). It is possible for recipients of support to experience harm when ‘supportive actions are incongruous with a needy individual’s expectations or personal coping style’ (Schilling, 1987, p. 24). Support responses to a bereaved person following the death of a loved one is an example, where the bereaved is encouraged to get on with life, or to find meaning in the death of the loved one; when the recipient does not respond as expected, the support person may withdraw their support or, conversely, the recipient might perceive the support as harmful (Schilling, 1987).

The social norm of reciprocity regulates supportive relationships, although in many relationships the social support is inequitably distributed, such as people who are dependent through intellectual, psychiatric or physical disability, and who need to ‘draw on social support resources they are unable to replenish [or reciprocate]’ (Schilling, 1987, p. 25). In some cases, the very reason for seeking support, such as to alleviate distress, may impact on the support (Sluzki, 2010, Vaux, 1988), such as chronic distress being likely to deplete support, possibly extinguishing the support behaviour and disrupting relationships with support persons (Vaux, 1988).

People seek support to alleviate distress, although the support they seek may be negatively impacted by distress (Sluzki, 2010; Vaux, 1988). Chronic distress is likely to deplete support, possibly extinguishing the supportive behaviour and disrupting relationships with support persons (Vaux, 1988).

There are many barriers and limitations to accessing, or to maintaining, social support, at each level of the ecosystem: individual, organisational, and attitudinal. Families and individuals with limited resources may have greater difficulty in locating and belonging to supportive networks, which has possible impacts on health and wellbeing, discussed in the following section.
Role of social support in health and wellbeing

There is sound evidence for the link between better health chances and participating in informal social networks, social activities, and in the community (Cattell, 2001). However, seen through an ecosystems lens, there are environmental, systems, and individual factors that may impact on physical and mental wellbeing, with the wellbeing of parents directly affecting the developmental health and wellbeing of their children (Jack & Jordan, 1999). Social support has been shown in numerous studies to be linked to psychological and physical health outcomes, with positive relationships being found between social support and mental health (Cohen, 2004; Cohen & Wills, 1985, Sluzki, 2010). Sluzki (2010) cited 35 studies (not exhaustive), conducted between 1949 and 2005, in which demographic and social network variables were correlated with health and wellbeing in children, in old age, on groups in differing socioeconomic sectors, on people with dementia, people relapsing from schizophrenia, and those who had suffered from a stroke, coronary heart disease, heart attack, and other conditions, including the common cold.

Early contributions on the moderating effects of social support on stress were made by Cassel (1976) and Cobb (1976). Cassel (1976) reviewed studies of people with various illnesses, and concluded that the factor common to these groups was their marginal status in society. The effect of support on wellbeing was demonstrated in a number of empirical studies cited by Cassel (1976), which used different research designs and different populations. For example, a cohort study of pregnant women examined complications of pregnancy as an outcome of lack of support. The study found that, of the 170 pregnant women who participated, 90% of those who had ‘high life change’ scores and had low social supports, had one or more complications of pregnancy. Among women who also had high life change scores, but had high social supports, 33% had pregnancy complications (Nuckolls, Cassel, & Kaplan, 1972, cited in Cassel, 1976).

Cobb (1976) took a life-cycle approach when reviewing the protective effects of social support from life in utero, to death. Beginning with the study cited above (Nuckolls et al., 1972) Cobb (1976) reviewed studies from pregnancy, birth, early life, transition to adulthood, hospitalization, illness recovery, life stress, alcoholism, affective disorder, employment termination, bereavement, aging and retirement, and threat of death, such as during armed combat, and concluded that the studies reviewed provided ‘hard evidence that adequate social support can protect people in crisis from a wide variety of pathological
states’ (p. 310). Cobb (1976) argued for the preventive role of social support in moderating the impact of crisis and change, and that practitioners could contribute to this by encouraging their ‘patients, both well and sick, how to give and receive support’ (p. 312).

Bosworth and Warner Schaie (1997) examined the relationship between morbidity and social networks and social environment in a community sample of 387 men and women aged between 36 to 82 years. Social network measures included number of friends, accessibility to confidants, and time spent at religious meetings and in social activities. Social environment measures included cohesion, conflict, expressiveness, achievement orientation, and cultural and recreational orientation. The health outcome variables included number of diagnoses, disease episodes, and hospital visits recorded over a one-year period. Differences were found for married and unmarried participants on the variable of social network, with married individuals having a greater social network incurring lower total care and outpatient costs and fewer primary care visits, while for unmarried individuals a lower perceived social environment was related to increased physician visits. Including married and unmarried participants, the number of hospital visits was found to be greater for those with fewer supports in their social environment (Bosworth & Warner Schaie, 1997).

In a more recent study of social relationships and health, Cohen (2004) examined social support, social integration, and negative interaction and concluded that greater social integration is better for health. Alternatively, the negative effects of social isolation cause disease, through effects on psychological states, which, in turn, impact on physical health. The association between social integration and morbidity and social integration and mortality ‘may be attributable to … the health-promoting mechanisms associated with integration and the disease-promoting mechanism that operates among the most isolated’ (Cohen, 2004, p. 680).

Berkman and Syme (1979) found evidence for the correlation between social support and mortality in their pioneering study of 7000 adults cited above. A social network index was created by aggregating data from surveys of participants’ marital status, extent of contact with friends and relatives, participation in formal and informal groups, and membership in a religious congregation. After controlling for age, gender, and prior health status, the social network index was found to be significantly related to mortality. Both men and women with limited social networks were twice as likely to die during the study period as those with robust social networks. These findings were confirmed in two
subsequent studies (House, Robbins & Mekner, 1982; Shoenbach, Kaplan, Friedman, & Kleinbaum, 1986).

The mediating effects on children’s mental health of family social support, and stress levels, was examined by Quinn et al. (2014). A US national sample of 3255 children and adolescents involved with child protective services was measured on three variables: social and familial risk, caregiver mental and physical health, and children’s mental health. Data analyses showed that the mental health status of the caregiver had a mediating effect on the relationship between high family stress and the internalisation of problems resulting in anxiety, withdrawal, and depression in children and adolescents, and a moderately mediating effect on the relationship between social support and problem internalisation. Caregiver mental health also had a moderately mediating effect on the relationship between low social support and the externalisation of problems seen in aggression, non-compliance, and impulsivity. Quinn et al., (2014) concluded that the study pointed empirically to the ‘substantial role of caregiver mental and physical health in a child’s life …[and] highlight[ed] the importance of intergenerational and social connections in the healthy well-being of caregivers and their children’ (p. 168).

**Direct and buffering effects of social support on parental stress**

Theories of social support, generally, see it as a health-sustaining phenomenon (Shumaker & Brownell, 1984). Social support is seen to have a ‘buffering’ effect in modifying or mitigating the deleterious effects of stress on health (Cassel, 1974; Cobb, 1976; Shumaker & Brownell, 1984). According to Lakey and Orehek (2011), the distinction between the main and buffering effects on health has played a ‘foundational role in shaping research and theory’ (p. 482). Cohen and Will’s (1985) review of research on the role of informal support found the buffering effect occurred ‘when the social support measure [used in the studies reviewed] assesses the perceived availability of interpersonal resources that are responsive to the needs elicited by stressful events’ (p. 310). The main effects occurred ‘when the support measure assesses a person’s degree of integration in a large social network’ (p. 310). From this they concluded that the support provided needed to match the needs of the individual and the situation. Thus the context for the support was important.

Koeske and Koeske (1990) studied the relationship between the direct and buffering effects of social support and parental stress. They interviewed 125 mothers with
children aged between nine months and 14 years. The social support items measured included available emotional supports, tangible supports such as childcare, help available from friends, relatives and neighbours, and availability of other adults to talk to about feelings about parenting.

Parental stress was measured by asking parents to rate aspects of child behaviour, and several dimensions of child development. Outcomes of parenting stress were measured by ratings on a parent satisfaction scale, a maternal self-esteem scale, and a scale which asked parents to rate the degree to which various problems had distressed them in the previous two weeks, such as headaches. They found a direct effect between the social supports identified by parents and satisfaction, self-esteem, and psychological symptoms, with higher social support correlating with higher satisfaction and self-esteem, and fewer symptoms, thus supporting the main effect model.

Koeske and Koeske’s (1990) analysis of the moderating effects of social support on the relationship between the stress and outcome measures found lower correlations for mothers with low levels of support. This supported the hypothesis that social support had a buffering effect on stress. Subsequent studies have found that social support provides a buffering effect for divorced fathers in coping with the common stressors of divorce (conflict with former spouse, family stressors, and fathers’ role overload) (DeGarmo, Patras, & Eap, 2008). Armstrong, Birnie-Lefcovitch, and Ungar (2005) found that social support was a ‘protective mechanism with main and buffering effects that can impact family wellbeing, quality of parenting, and child resilience’ (p. 269).

Social support and stress have been shown to individually influence parenting, with high levels of parenting stress having undesirable outcomes for children (Respler-Herman, Mowder, Yasik, & Shamah, 2012). Parents with high levels of social support have been found to experience low levels of parenting stress, which leads to positive effects on parenting (Östberg & Hagekull, 2000).

The moderating effect of informal support, and caregiver perceptions of the child as making a positive contribution to the family, on caregiver stress was found in a study of families having a child with an emotional disorder (McDonald, Gregoire, Poertner, & Early, 1997). Primary caregivers for 259 children aged between four and 12 years completed mailed questionnaires which included measures of child characteristics, family characteristics, social support, formal support, coping behaviour, perceptions of the child,
and caregiver stress. The informal support of family and friends and perception of the child as making a positive contribution to the family were found to be interrelated, which contributed to enhancing coping strategies and reducing caregiver stress (McDonald et al., 1997).

Shumaker and Brownell’s (1984) framework shows the potential effects on recipients of social support resources and can be used to illustrate the main and buffering effects of social support on parents in the Koeske and Koeske (1990) study. For example, the resource of ‘reassurance of worth’ (as a parent) can have the effect of enhancing self-confidence, a *main* effect. Where mothers reported feeling stressed by the behaviour of their children, those with higher social supports reported experiencing less stress (Koeske & Koeske, 1990). Social support in this instance had a *buffering* effect which could be related to the resource of ‘verbal information regarding severity of threat and its objective reality, and potential coping strategies’ (Shumaker & Brownell, 1984, p. 27), in turn having the effect of increasing parenting confidence in raising a child.

**Support for families living with a family member with mental illness**

The need for family and community support for families having a family member with a mental illness arose from the move of people with a mental illness from institutions to living in the community (Gottlieb, 1983; Falloon, 2003). The shift to community-based treatment led to greater involvement of their families in their lives, whether or not they lived together. In turn, this was stressful for families and, over time, led to the development of family interventions, which were found to be beneficial through the peer support they offered, as well as opportunities to learn from one another and, on occasions, professionals about the mental illness affecting their family member (Falloon, 2003). The social support family members received, and still receive, could be categorised as types of support shown in Table 4.1: emotional (Hinson Langford et al., 1997), informational (Wills, 1985), and relational (Heaney & Israel, 2008).

Research concerning support for each of the groups encountered in this study, where it exists, might be specific, such as support for grandparents (Gerard, Landry-Meyer, & Roe, 2006), or part of a general study into the experiences of parents with mental illness (Stanley, Penhale, Riordan, Barbour, & Holden, 2003) or the experiences of
children and young people who have a parent with mental illness (Aldridge & Becker, 2003).

A study of the responses to families where parents had a mental illness (Stanley et al., 2003) defined supports systems as ‘networks of friends or family members that the women could draw on for help’ (p. 59). The 11 women in that study all reported a diagnosis of mental illness, with six mothers having some or all children with them, with the remaining children being either adopted, or in care. The women reported that the support of other family members provided the buffering effect against the effects of stress, with the support being instrumental (practical) and expressive (emotionally based) (Stanley et al., 2003). Seven women lived some distance from family members, but valued the support received when they needed it. Three women were unable to identify someone with whom they had a close and confiding relationship, and experienced high levels of social isolation (Stanley et al., 2003).

In an in-depth research study of children caring for parents with severe and enduring mental illness (with the term ‘young carers’ being used by the authors), Aldridge and Becker (2003, p. xii) interviewed 40 families including 40 young carers aged between 10 and 19 years. The young people were not questioned directly about their sources of support, but the study findings showed that almost half of the young carers had limited social opportunities because they were ‘fearful of ridicule or discriminatory responses from their peers, and often did not easily make or trust friends’ because of the mental illness of their parent (Aldridge & Becker, 2003, p. 91). Worries about their parents, and isolation from peers, could be detrimental to the wellbeing and development of the young people.

**Conclusion**

This chapter has presented definitions and theories of social support, and highlighted the barriers and limitations from an eco-systems perspective. The acknowledged relationship between social support and physical and mental health and wellbeing shows how individuals and families with adequate social support will have more resilience to cope with change and crises, than those without. Conversely, people with physical or mental ill-health or disability may have difficulty in locating and continuing supportive relationships and networks.
The following chapters set out the policy and service context affecting the families in this study. This includes national and state policies and services relating to families and carers of people with mental illness and family support for families with children. Chapter 5 discusses mental health policy and Chapter 6 policy relating to social support for vulnerable families.
Chapter 5

Mental health policy and services in Australia

In Australia mental health policy is determined by two levels of government: Federal and state or territory. Hence there are numerous policies relating to families and carers of people with mental illness that fall under the federal jurisdiction, and others at the state or territory level. This chapter discusses Federal (Commonwealth) mental health policy and that of New South Wales, where the study was conducted. Family support policy is discussed in Chapter 6.

Two significant institutional and political changes have influenced social policy for, and service provision to, children and families living with a family member with a mental illness. The first was deinstitutionalisation, which, over a period of 30 years, moved people with mental illness out of large mental institutions into the community and resulted in many families having to care for family members who were mentally ill. The second was the introduction of a National Mental Health Policy in 1992 and a series of five-year plans for its implementation that became known as the National Mental Health Strategy. Of particular importance for this study, was the recognition given to families caring for people with mental illness in successive mental health policies.

Preceding the reforms in mental health was the Australian federal government’s withdrawal from the national family support program in the mid-1970s (Australian Catholic Social Welfare Commission, 1997). This meant the responsibility for family support services was transferred to the state and territory governments (as discussed in Chapter 6). This chapter examines the history of mental health reform in Australia to the present day as one aspect of the policy context in which this study was conducted. The chapter begins by describing the history of informal family care for people with mental illness. In comparison, family support services are a relatively recent phenomenon, and in this context refers to a particular service provided to families under time-limited state and federally funded programs.
History of family care for family members with mental illness

Across centuries and cultures, the family has been responsible for members with mental illness. Segregation into institutions began in the Middle Ages and was the main mode of treatment until the second half of the 20th century when deinstitutionalisation began (Porter, 2002). The introduction of deinstitutionalisation shifted the responsibility for caring for people with mental illness back onto families, given community services were unprepared for this change and there was a shortage of suitable support, accommodation, and treatment services in the community (Johnson, 1990). Homelessness was the only option for many who did not have supportive families.

Since Greek and Roman times, families have borne the responsibility of caring for those with mental illness. Plato in the Laws wrote, ‘If a man is mad he shall not be at large in the city, but his family shall keep him in any way they can’ (in Porter, 2002, p. 89). Eight hundred years ago segregation of the mentally ill was introduced, with confinement into towers or dungeons beginning in medieval times. The first European asylum for the insane was established in Valencia in 1409 (Arboleda-Flórez, 2008). In London, a religious house – St. Mary of Bethlehem – founded in 1247 was ‘catering for lunatics by the late fourteenth century’ (Porter, 2002, p. 90). In 1770, the first ‘madhouse’ in the USA was established in Hull, Massachusetts (Falk, 2001). Further asylums were established by religious charities in England in the 18th century, followed by the development of asylums in North America in the 19th century. The number of asylums and patients increased, influenced by faith in institutional solutions to social problems ‘spawned by demographic change, urbanization, and industrialization’ (Porter, 2002, p. 112). Treatment shifted from ‘moral’ and personal therapy to pharmacological regimes, and with that shift emerged the ‘great divide’ between ‘the rational and the rest’ (Porter, 2002, p. 122). The birth of asylums was the product of compassion, but these refuges quickly developed into prison-like structures of institutionalised social exclusion (Vives, in Arboleda-Flórez, 2008).

The late 18th century brought about reforms which repudiated the use of custodial care, medication, and restraint, and advocated the humane treatment of inmates (Porter, 2002). According to moral reformers, such as Philippe Pinel, a doctor in France, and William Tuke, a Quaker in England, this entailed the reanimation of a person’s reason, which, it was thought, was best achieved in the closed environment of the asylum (Porter, 2002). Legislation was passed in France, Belgium, and England to establish facilities to
care for the mentally ill, and to safeguard them from improper confinement and abuse (Porter, 2002). By the late 19th century, optimism about the efficacy of treatment in asylums gave way to pessimism, as the ‘moral therapy’ of kindness and humanity was ineffective for many. The number of people housed in these institutions increased with each successive decade, as they were seen as a threat to society. Insanity was believed to be ‘chronic … ingrained, constitutional, and probably hereditary’ (Porter, 2002, p. 119). As little could be done for the insane, not only would institutionalisation protect inmates but also the broader community by preventing the contagion of mental disorders (Porter, 2002).

Deinstitutionalisation was an unplanned response to overcrowding in mental hospitals and the high cost of maintaining deteriorating buildings, as well as ongoing exposés of the heinous conditions in which asylum patients lived (Johnson, 1990). Also, evolving knowledge about mental illness, the advent of psychoanalysis and, later, a new generation of treatment drugs, meant mental patients discharged back into ‘the community’ could be treated at community mental health centres run by mental health experts. As Lieberman (2015) observes, ‘psychoanalysis offered a distinct benefit for … [the psychiatric] profession: a way out of the asylum’ (p. 71). In reality, however, deinstitutionalisation meant a life of poverty and homelessness for many without families, and many families were forced to assume responsibility for their mentally ill family members (Johnson, 1990).

The transfer of the primary caring role to families and communities precipitated the need for supportive community services to relieve the burden of care (Östman & Hansson, 2004). Community-based, self-help groups for carers of people with a mental illness grew to support the needs of ill-equipped carers, who found themselves with new responsibilities for which they had no experience or training (Bachrach, 1976; Snowdon, 1980). Doll’s (1976) study of 125 significant others found the return of patients to their families was ‘causing serious crises in the lives of those families … now responsible for the care and rehabilitation of relatives released from mental hospitals’ (p. 183). Following the failure of community services, 25 years later Lamb and Bachrach (2001) called for greater involvement of families in caring for mentally ill family members due to their ‘expert knowledge that is otherwise unavailable to service providers’ (p. 1043). Several studies, however, have reported on the severe physical, mental, and financial difficulties
experienced by family members caring for loved ones with a mental illness (Cummins et al., 2007; Edwards et al., 2008).

**Mental health policy reform in Australia**

This section provides a brief overview of the evolution of mental health reform over the past 50 years, from deinstitutionalisation to family and community-based care to the development and revision of successive mental health policies and plans, the increasing participation of consumers and carers, and the more recent adoption of recovery-oriented approaches.

**1960s: Deinstitutionalisation**

An early impetus for mental health reform in Australia was the closing of large institutions and return of people with mental illness back into the community. The impact of this on consumers, their families, carers, and mental health services over the following decades is the focus of this chapter.

**1970s: Community care and rise of the consumer movement**

Community care in mental health in the 1970s comprised state provision of professional care through accessible, multidisciplinary services designed to detect, treat, and prevent mental illness. In the late 1970s, the growing mental health consumer movement began to challenge the public healthcare bureaucracy arguing that health services were not responsive to consumer needs (Henderson, 2005). It called for ‘personal empowerment and freedom of choice’, which later became embedded in mental health policy as consumer participation and choice.

**1980s: Calls for a national approach to mental health**

In the 1980s, several professional groups, including the Royal Australian and New Zealand College of Psychiatrists, and consumer forums, such as the Mental Health Consumer Outcomes Task Force, called for the establishment of a national approach to mental health.
1990s: National Mental Health Strategy

Following adverse publicity and a series of public inquiries into mental health services, as well as pressure from professional groups and service providers, the beginning of the mental health reform process in Australia may be traced to the landmark launch, in 1992, of the National Mental Health Policy. The policy was implemented through a series of five-year National Mental Health Plans, known as the National Mental Health Strategy. Whiteford and Buckingham (2005) observed that:

The changes that followed the introduction of the Mental Health Strategy needed to address the legacy of 30 years of deinstitutionalisation, which saw the number of psychiatric beds decrease from 30 000 to about 8000, with limited development of community services, and a doubling of Australia’s population (p. 396).

At its launch in 1992, the Strategy comprised four key documents:


The policies and related initiatives published during the 1990s are shown in Table 5.1 (on p. 95).

Mental Health Statement of Rights and Responsibilities, 1991

The publication of the Mental Health Statement of Rights and Responsibilities followed a consultative process over several years between states and territories and consumer and professional groups (Mental Health Consumer Outcomes Taskforce, 1991). As well as establishing the rights and responsibilities of consumers, it established the rights of carers of people with mental illness to comprehensive information, education, training, support, respite care, and counselling.

National Mental Health Policy, 1992

The aims of the first National Mental Health Policy (Australian Health Ministers, 1992a) were to; (i) promote the mental health of Australians, (ii) prevent, where possible, the
development of mental disorders, (iii) reduce the impact of mental disorders on individuals, families, and communities, and (iv) guarantee the rights of people with mental illness. Key measures included multifaceted approaches to ensure access to services and opportunities for people with mental illness to achieve personal growth, strategies to reduce the stigma of mental illness which led to social isolation and discrimination and exclusion from services, and adequately resource mental health services.

Whiteford, MacLeod, and Leitch (1993) noted the National Mental Health Policy introduced in 1992:

intended to set clear direction for the future development of mental health services within Australia. The Policy recognises the high prevalence of mental health problems and mental disorders in the Australian community and the impact of these on consumers, carers, families and society as whole. It also clearly accepts the need to address the problems confronting the promotion of mental health and the provision of mental health services (p. 186).

It aimed to improve the quality and quantity of mental health services in Australia (Whiteford & Buckingham, 2005).

**First National Mental Health Plan, 1992**

The First National Mental Health Plan commenced in January 1993 with activities set out for the following five years. They included structural and system reform, standards, consumer rights, data collection, legislation, and resource priorities. Commonwealth and state and territory roles and responsibilities were also clarified as the basis for the mental health reforms (Australian Health Ministers, 1992b). Henderson (2005) observed that the First National Mental Health Plan:

focused upon evaluation of existing services, community attitudes to mental illness and the rights of the mentally ill. In contrast, the period of the second five-year plan …. saw the publication of materials concerned with the development of quantifiable outcomes through casemix funding, quality control measures, and the development of benchmarks and standards of care (p. 248).
Medicare Agreement Act, 1992

Medicare is Australia’s national universal health insurance system, and commenced in 1975. Under Medicare:

all Australians are guaranteed free treatment based on clinical need in public hospitals (operated by the states) with subsidized access to primary care, private specialist care (including diagnostics), and pharmaceuticals ... Australia spends approximately 9% to 10% of gross domestic product on health, split approximately 70%:30% public:private (Nicholson, Jackson, Marley, & Wells, 2012, p. S18).

The Medicare Agreement Act (Department of the Parliamentary Library, 1992) revised the funding arrangement between the Commonwealth and states and territories introduced as part of the mental health reforms. It provided a new set of national health (and mental health) goals and targets.

Report on the National Inquiry into the Human Rights of People with Mental Illness, 1993

Reform was spurred on by the publication of the report of the National Inquiry into the Human Rights of People with Mental Illness (Human Rights and Equal Opportunities Commission (HREOC), 1993), which drew public attention to widespread abuse of the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (United Nations, 1991a), to which Australia was a signatory. The Inquiry led to the development of a framework for reform in mental health and the development of the National Mental Health Policy and First National Mental Health Plan (see above).

National Standards for Mental Health Services, 1997

As part of the national mental health strategy, the Australian Health Ministers’ Advisory Council National Mental Health Working Group (1997) auspiced the development of national standards for mental health services, which could be applied to mental health services across Australia. The standards emphasised positive outcomes for consumers and carers, with one standard specifically addressing consumer and carer participation. The Standards were revised in 2010, as discussed below.
**Evaluation of the National Mental Health Strategy, 1997**

To complement the regular National Mental Health Reports which used data from states and territories to monitor yearly progress of each jurisdiction in implementing the National Mental Health Strategy, independent evaluations were conducted to review progress and outcomes (National Mental Health Strategy Evaluation Steering Committee (NMHSESC), 1997). The final report noted that, during the five years of the Strategy (1992-1997), ‘substantial changes had occurred in the structure and mix of public mental health services’ (NMHSESC, 1997, p. 1). However, access to, and the quality of, mental health services was poor, with staff having ‘stigmatising attitudes’ and carers feeling they had been ‘left behind’ in service development processes (NHMSESC, 1997, p. 1). This experience was reflected in Lammers and Happell’s (2004) qualitative study of consumers’ and carers’ perceptions of their participation in the service system following the mental health reforms. While consumers identified an increase in opportunities for their participation, carers ‘described very little opportunity for participation at any level’ (p. 261). The final report set out nine future directions, including ‘strengthening the role of primary care’, with the relationships between general practitioners and specialist mental health services being ‘relatively undeveloped in Australia’, whereas ‘general practitioners carry the burden of responding to the majority of mental health need in the community’ (NMHSESC, 1997, p. 29).

**Second National Mental Health Plan, 1998**

Following the evaluation of, and final report on, the first plan, a Second Mental Health Plan (1998-2003) (Australian Health Ministers, 1998) consolidated existing reforms and introduced quality control measures and benchmarks for mental health services. One of the priority areas for reform in the second plan was mental health promotion and prevention. It introduced two documents outlining the foundations of, and actions for, mental health promotion, prevention, and early intervention discussed below (Commonwealth Department of Health and Aged Care, 2000a, 2000b).

The Second National Mental Health Plan identified children of parents with mental illness as one of the key groups for selective mental illness prevention measures (Australian Health Ministers, 1998). Families and children participating in the present study did so as clients of a program which was funded to build resilience and coping skills.
Table 5.1: National mental health policies and provisions for carers and families of people with mental illness 1990s

<table>
<thead>
<tr>
<th>1990s</th>
<th>Policy document</th>
<th>Description</th>
<th>Provision for carers and families</th>
</tr>
</thead>
<tbody>
<tr>
<td>1992</td>
<td>National Mental Health Strategy (NMHS) contained four documents:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Mental Health Statement of Rights and Responsibilities (Mental Health Consumer Outcomes Task Force, 1991)</td>
<td>Outlined the civil and human rights underpinning the NMHS.</td>
<td>The Statement set out carer’s rights to information and consultation with professionals, and to access to individual support.</td>
</tr>
<tr>
<td>3.</td>
<td>First National Mental Health Plan, 1993-1998 (FNMHP) (Australian Health Ministers, 1992b)</td>
<td>Described the five-year plan for implementing the NMHP aims and objectives</td>
<td>The Plan set out plans for the availability of respite services and education for carers. None of the above three documents referred to families or family members</td>
</tr>
<tr>
<td>4.</td>
<td>Medicare Agreement Act (1992) - funding agreement between the Commonwealth and states and territories</td>
<td>Outlined the funding arrangements to support the agenda for mental health reform</td>
<td></td>
</tr>
<tr>
<td>1993</td>
<td>Human Rights and Equal Opportunity Commission (HREOC) (1993): Inquiry into the Human Rights of People with Mental Illness</td>
<td>Set out anecdotal and documented reports of abuse of the UN Principles on the Rights of the Mentally Ill to which Australia is a signatory. The Inquiry led to a framework for reform and the NMHP and FNMHP</td>
<td>Found that family members in caring roles experienced adverse effects on physical and mental health, and financially; recommended support, respite, information, and consultation for and with family members</td>
</tr>
<tr>
<td>1997</td>
<td>National Standards for Mental Health Services (Australian Health Minister’s Advisory Council, 1997) (revised and replaced in 2010)</td>
<td>A guide to service enhancement, or development of new services, and to inform consumers and carers about expectations they could have of mental health services. Standard 3: Consumer and Carer Participation</td>
<td>Required that mental health services have policies to facilitate involvement of carers in all aspects of service delivery. Families were not referred to</td>
</tr>
<tr>
<td>1997</td>
<td>Evaluation of the National Mental Health Strategy (National Mental Health Strategy Evaluation Steering Committee, 1997)</td>
<td>Review of progress of National Mental Health Strategy</td>
<td>The Evaluation noted that substantial changes had occurred but carers felt they had been ‘left behind’ in these changes.</td>
</tr>
<tr>
<td>1998</td>
<td>Second National Mental Health Plan, 1998-2003 (SNMHP) (Australian Health Ministers, 1998)</td>
<td>The second Plan built on achievements of the first, and was broadened to more explicitly include disorders in addition to psychotic disorders and depression</td>
<td>Carers and families were to have a key role in influencing decisions at all levels</td>
</tr>
</tbody>
</table>
2000s: Further embedding mental health reform

The years 2000 to 2009 saw a commitment to mental health promotion, prevention, and early intervention; increased emphasis on the application of outcome measures; and growing recognition of the needs of children, families, and carers of people with mental illness, and their participation in service provision. Policies and related initiatives published in the 2000s are shown in Table 5.2 (on p. 101).

Mental health promotion, prevention, and early intervention initiatives were informed by epidemiological studies of adults and children conducted in the late 1990s, which found significant levels of unmet need among those meeting mental health diagnostic criteria (Whiteford & Buckingham, 2005). Two documents provided the conceptual and theoretical foundation: the Monograph and National Action Plan.

Promotion, Prevention and Early Intervention for Mental Health Monograph, 2000

The PPEIMH Monograph (Commonwealth Department of Health and Aged Care, 2000a) considered environmental and psychosocial influences on mental health that provided the rationale for a multisectoral approach to mental health and wellbeing. The Monograph distinguished between universal and selective interventions to prevent the onset of mental illness, and set out the protective and risk factors occurring at the individual, family, school, and community levels.

National Action Plan for Promotion, Prevention and Early Intervention for Mental Health, 2000

The National Action Plan (Commonwealth Department of Health and Aged Care, 2000b) set out promotion, prevention and early intervention actions for groups across the lifespan, and priority populations. An example of a universal mental health promotion program is MindMatters, a school-based program to promote mental health and identify and respond to young people with mental illness. It was introduced into secondary schools in 1997-1998 and has been evaluated positively by students and teachers alike (MindMatters Evaluation Consortium, 2000). The website continues to provide online training for teachers and support to assist them in introducing MindMatters into their schools.
National Practice Standards for the Mental Health Workforce, 2000

The National Practice Standards for the Mental Health Workforce highlighted the education and training of the mental health workforce as a significant part of the reform process (Commonwealth Department of Health and Ageing, 2002). The Standards resulted from a collaborative project by representatives from mental health nursing, occupational therapy, psychiatry, psychology, and social work. Twelve Practice Standards were set out under the headings of rationale, knowledge, skills, and attitudes. They emphasised the: (i) development of therapeutic alliances with family members; (ii) provision of information about mental health problems and disorders, and self-help organisations; and (iii) importance of support services for families living with mental illness. Standard 2 focused on consumer and carer participation, with workers expected to understand the needs of carers and family members, have the skills to work collaboratively with them, and positive attitudes towards the involvement of family members, carers, and consumers.

Third National Mental Health Plan, 2003

Under the influence of neoliberal welfare reform, the third National Mental Health Plan 2003-2008, (Australian Health Ministers, 2003) further emphasised measurement, ratings, and outcomes. The direction set was the work of mental health bureaucracies in the eight Australian states and territories, together with the federal Department of Health and Ageing (Rosenberg, 2011). The third plan noted the service quality agenda needed to:

be broadened from its current emphasis on service inputs and structure to service impacts and outcomes. This can be achieved through the development of a culture of measurement and the establishment of consumer and clinician rated measurement systems, national benchmarking of mental health services, and agreement on and establishment of appropriate levels and mix of services (Australian Health Ministers, 2003, p. 25).

It included the development of ‘routine outcome measurement systems in the mental health sector’, together with a national strategy ‘for database development, data analysis (which may include normative comparisons and benchmarking exercises), dissemination and training’ (Australian Health Ministers, 2003, p. 25). In relation to
funding, key directions included continuing the development of casemix classifications and improving the capacity of the private sector through funding models and related reform (Australian Health Ministers, 2003). The third plan continued to promote the role of families as carers:

With the move to more community-focused treatment for people with mental illness, the enhanced role of carers must be recognised and supported. The needs of families and carers, particularly where children are carers, should be acknowledged and services put in place to support their efforts and ensure that their own wellbeing is maintained. Initiatives to include families and carers in treatment planning are essential (Australian Health Ministers, 2003, p. 23).

National Action Plan on Mental Health, 2006

In 2006 a ‘new player’ entered the mental health debate, the Council of Australian Governments (COAG). It imposed its own agenda and priorities on the reform process, previously controlled by the federal, state, and territory bureaucracies (Rosenberg, 2011). The five-year National Action Plan on Mental Health, 2006-2011 (COAG, 2006) was quite separate to existing national and state mental health plans and policies (Rosenberg, 2011). Each of the nine jurisdictions – federal, and eight states and territories – had ‘complete sovereignty’ (p. 14) over selection of areas for spending under the COAG National Action Plan, which aimed to respond to perceived gaps in services, including the:

- Availability of counselling provided through General Practitioners who could refer clients to allied health professionals.
- Funding of the community-managed organisations sector to deliver employment, support, and community access programs (Bateman & Smith, 2011).

Better Access to Mental Health, 2006

An initiative under the National Action Plan on Mental Health 2006-2011 (COAG, 2006) was the Better Access to Mental Health program established in response to the low treatment rates for common mental disorders, such as anxiety, depression, and substance use disorders (Department of Health and Ageing, 2013). General Practitioners could refer people with these diagnoses to accredited allied health professionals in private practice,
such as social workers and psychologists, for focused, time-limited (ten sessions in a calendar year) psychological interventions, subsidised by Medicare. Practitioners could elect to bulk bill or, where they did not, clients had to pay the gap between the Medicare rebate and cost of the session. For reasons unknown, social workers were removed from the list of providers in 2010; an action campaign launched by the professional association of social workers had them reinstated as accredited providers within four months (Mendes, McCurdy, Allen-Kelly, Charikar, & Incerti, 2015).

Second National Mental Health Policy, 2008

The second National Mental Health Policy 2008 (Australian Health Ministers, 2009) emphasised a whole-of-government approach which included services outside the health portfolio, such as housing, employment, emergency relief, correctional, educational, and community services. The policy also highlighted the promotion of mental health, prevention of mental disorders, and reduction of the impact of mental illness on individuals, families, and communities, including partners, relatives, and children caring for a family member with mental illness.

Fourth National Mental Health Plan, 2009

Changes in terminology were evident from the third to the fourth National Mental Health Plan (Commonwealth of Australia, 2009b). While the third plan had been organised under four themes, with several outcomes for each theme, measured by increases, reductions, or improvements, the fourth plan contained five Priority Areas. Changes were to be measured by outcome indicators, such as participation rates (people with mental illness of working age in employment), proportions, and percentages. The fourth plan emphasised the role of families in recognising and supporting a person in relapse, and acknowledged the ‘considerable burden [this could place] on family members and sometimes the most effective way to support a person at risk of relapse will be to support the family system around them’ (Commonwealth of Australia, 2009b, p. 36). In short, the fourth plan further embedded individual responsibility, acknowledged the role of families in supporting a mentally ill family member, and extended welfare to work to mentally ill people on disability payments through a plan to increase their workplace participation rates.
2010-present: Where to from here?

Since the early 1990s there had been a substantial increase in the level of policy attention and funding given to mental health in Australia, but this had not led to a substantial decrease in the incidence rates of mental illness and suicide, the number accessing mental health services, or to consistent and effective responses received by those who had sought services (Medibank Private Limited and Nous Group, 2013). An Australian Government (2011) budget paper on national mental health reform acknowledged that ‘people with mental illness have to deal with fragmented and uncoordinated systems’ (p. 5). The playing field had changed as mental healthcare devolved from the state to the private sector. Though the Australian welfare system had always comprised a ‘mixed economy’ of government, informal, voluntary, and commercial sectors (Henderson, 2005, p. 244, citing Dean & Thompson, 1996), user-pays services became more common with the consumer choice model. However, the biggest change in recent years has been the focus on primary healthcare.

National Health and Hospitals Reform Commission, 2009

The National Health and Hospitals Reform Commission (NHHRC) was established by the federal Labor government in 2008, and a year later delivered the report entitled A Healthier Future for All Australians (NHHRC, 2009). The report suggested major structural reform of the healthcare system, including ‘the Commonwealth government taking responsibility for the policy and public funding of primary health care services’, (NHHRC, 2009, p. 102). The policies and related initiatives from 2010 to date are shown in Table 5.3 (on p. 111).

National Primary Health Care Strategy, 2010

In Australia, ‘primary healthcare is largely delivered through two parallel systems: Medicare supported primary care delivered by fee-for-service general practitioners, and state funded and managed community health services’ (Wiese, Jolley, Baum, Freeman, & Kidd 2011, p. 995). Following the NHHRC (2009) report, the Department of Health and Ageing (2010) developed the first National Primary Health Care Strategy Building a 21st Century Primary Health Care System, which identified regional integration, improved access and reduced inequity, and prevention, among its key building blocks and
Table 5.2: National mental health policies and provisions for carers and families of people with mental illness 2000s

<table>
<thead>
<tr>
<th>2000s</th>
<th>Policy document</th>
<th>Description</th>
<th>Provision for carers and families</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>Promotion, Prevention and Early Intervention for Mental Health. A Monograph (Commonwealth Department of Health and Aged Care, 2000a)</td>
<td>Sets out the theoretical and conceptual framework for a population approach to mental health promotion</td>
<td>Children and families were included in the life-span approach taken in the Monograph</td>
</tr>
<tr>
<td></td>
<td>National Action Plan for Promotion, Prevention, and Early Intervention for Mental Health (Commonwealth Department of Health and Aged Care, 2000b)</td>
<td>Outlined a strategic framework and plan of action based on the above Monograph</td>
<td>Included ‘consumers and carers’ as one of 15 priority groups; no reference to family members as carers</td>
</tr>
<tr>
<td>2002</td>
<td>National Practice Standards for the Mental Health Workforce (Commonwealth Department of Health and Ageing, 2002)</td>
<td>Set out the attitudes, knowledge, and skills mental health practitioners required to work respectfully with consumers and carers</td>
<td>Standard 2: Consumer and Carer Participation set out general responses to ‘consumer and carer participation’; did not contain a Standard on families</td>
</tr>
<tr>
<td>2003</td>
<td>Third National Mental Health Plan, 2003-2008 (Australian Health Ministers, 2003)</td>
<td>Set out principles and priority themes for a population health framework for mental health</td>
<td>Made explicit reference to carers and families, including children – their need for support, information, and respite</td>
</tr>
<tr>
<td>2006</td>
<td>National Action Plan on Mental Health, 2006-2011 (Council of Australian Governments, 2006)</td>
<td>Development of the COAG Action Plan was a response to the view that the mental health reforms had been underfunded (Meadows et al., 2007)</td>
<td>Families, children and young people were included in the measure which addressed mental health promotion, prevention, and early intervention</td>
</tr>
<tr>
<td></td>
<td>Better Access to Mental Health was included as an initiative in this Plan</td>
<td>Enabled accredited mental health social workers, along with other allied healthcare providers such as psychologists, to provide community-based mental health services funded by Medicare</td>
<td>Better Access services may be accessed by children, young people and adults, with a referral from a general practitioner</td>
</tr>
<tr>
<td>2009</td>
<td>Second National Mental Health Policy, 2008 (Australian Health Ministers, 2009)</td>
<td>Embedded a whole-of-government approach and gave greater prominence to workforce issues</td>
<td>Specified the needs and rights of carers to information and entitlements and acknowledged family members and friends might have a caring role</td>
</tr>
<tr>
<td></td>
<td>Fourth National Mental Health Plan, 2009-2014 (Commonwealth of Australia, 2009b)</td>
<td>Operationalised a population health framework and brought together mental health reforms and policy directions in other sectors, such as housing</td>
<td>The need for support for families and carers was acknowledged in the priority area of prevention and early intervention</td>
</tr>
</tbody>
</table>
priority areas. In relation to mental health, the Australian Government stated its commitment to ‘taking responsibility for primary mental health services for people with mild to moderate common disorders, such as anxiety and depression’ (Department of Health and Ageing, 2010, p. 29).

The structural arrangement for the integration and coordination of the organisations and service providers operating within primary healthcare was the establishment of 62 interdisciplinary primary healthcare organisations, known as Medicare Locals, which have been described as ‘meso-level’ intermediate structures sitting between government and local primary healthcare providers (Gable & Foster, 2013). The role of Medicare Locals was to support service coordination and respond to population-based health planning indicators at the local level. The nongovernment, community-managed mental health sector was treated as having ‘marginal relevance’ alongside Medicare Local operations (Bateman & Smith, 2011).

Funding from the Commonwealth to the Medicare Locals was provided for administration and delivery for the Access to Allied Psychological Services (ATAPS) program, first established in 1992 to provide low cost, short-term interventions to adults with mental illness (Department of Health and Ageing, 2013). General Practitioners referred people requiring psychological services to the ATAPS program through Medicare Locals who allocated the client to a registered or accredited mental health professional, such as a psychologist, social worker, mental health nurse, occupational therapist, or Aboriginal and Torres Strait Islander health worker (Department of Health, 2014). In 2010, ATAPS was expanded to include children and their parents for individual and family interventions (Department of Health and Ageing, 2013).

A review of the Medicare Local initiative in 2014, requested by the Minister for Health, found that in general Medicare Locals had not been clear about their purpose, patient care had not improved, and a change in their structure and function was recommended (Horvath, 2014). In response, the Liberal government announced that 31 Primary Health Networks (PHNs) would replace Medicare Locals, the key difference being they would ‘focus on improving access to frontline services, not backroom bureaucracy’ (Ley, 2015, p. 1).
Carer Recognition Act, 2010

The Carer Recognition Act (Parliament of the Commonwealth of Australia, 2010) established a national legislative framework to increase awareness of 2.9 million carers in Australia, including those caring for a person with mental illness, and acknowledged the role of children and young people. The Act defined a carer as an individual providing personal care, support, and assistance to another individual because that person has a disability, medical condition, mental illness, or age-related frailty. The Act specifies that the carer status does not accrue automatically to relatives or partners living with the person requiring care.

National Standards for Mental Health Services, 2010

The National Standards for Mental Health Services (Commonwealth of Australia, 2010) followed a review of the 1997 standards and included a new standard relating specifically to carers. Mental health services were required to have policies and service-delivery protocols to enable the effective identification of, and provision of support for, carers, including children who were carers. The involvement of carers in mental health service policy development and evaluation was encouraged, together with support for carers participating in advocacy roles.

Roadmap for National Mental Health Reform, 2012

The Roadmap for National Mental Health Reform, 2012-2022 (COAG, 2012) had six priority areas, including a focus on person-centred care, prevention, and improving the social and economic participation of people with mental illness, with performance indicators for each priority area.

National Practice Standards for the Mental Health Workforce, 2013

The National Practice Standards for the Mental Health Workforce (NPSMHW) (Victorian Government Department of Health, 2013) followed a review of, and consultation process on, the first NPSMHW (Commonwealth Department of Health and Ageing, 2002). It included an additional practice standard on working with people, families, and carers in recovery-focused ways. Under this standard the mental health practitioner has responsibility to follow a strengths-based approach with the person, respect the role and needs of family members and carers, and facilitate their involvement in decision making with the agreement of the person with mental illness.
Focus on carers

Given the focus of this study, the following section discusses the focus within policy and service provision on carers. It briefly examines:

- Recognition of carers and families of people living with mental illness
- Support for carers
- Consumer participation
- The recovery-oriented approach.

Recognition of families and carers of people with mental illness

Of particular relevance for this study was the recognition of the caring role of families in mental health policy. As early as the 1970s, mental health service users and their families had become involved in self-advocacy (Snowdon, 1980). The first official documents on consumer involvement emerged in the 1980s, for example, the report of the Richmond inquiry into mental health services in New South Wales (Richmond, 1983). By the late 1980s, ‘families of the mentally ill had been constructed as carers and their role incorporated into policy documents’ (Henderson, 2005, p. 251; see also Bland & Foster, 2012). This had occurred in the administrative context of the closure of stand-alone psychiatric hospitals, their relocation to general hospitals, and consequent reduction in hospital beds (by 63%). This enabled the release of funds for community services, including outpatient care, which occurred in tandem with the increasing shift ‘to the provision of services across the public sector, nongovernment organisations, and the family’ (Henderson, 2005, p. 249). The definition of community care altered with the move to ‘greater individual and family responsibility for the management of mental illness’ with ‘families as a private source of care’ incorporated ‘into formal psychiatric management structures’ (Henderson, 2005, p. 249).

Though a seeming win for the consumer movement, critics of neoliberal welfare reform generally were quick to associate this change with the consumer-choice model, wherein individual consumers bore the responsibility for their wellbeing (Henderson, 2005).

Henderson’s (2005) critical analysis through a neoliberal prism noted carers were required to inform and educate themselves and enforce medical advice; as informal carers,
they were morally obliged ‘to manage the health and well-being of the mentally ill’ (p. 252). The implication was that, ironically, they no longer had a choice as this requirement devolved the responsibility for care onto them. Hence, though carers had rights to receive services to assist them in caring for and supporting their family members, they, nevertheless, were primarily responsible for delivering this care, albeit with support from government. In effect, informal carers no longer had a choice (Henderson, 2005, citing Dean & Thompson, 1996). Increasing policy references to family members as carers and partners in care, on the one hand, and their responsibilities and obligations, on the other, highlighted the inherent tensions: they had gained recognition as carers with particular needs, but this was accompanied by the expectation that they would support and care for family members (Bland & Foster, 2012).

In 2010, the Australian parliament introduced the Carer Recognition Act 2010, to increase awareness of the role of carers, including those caring for a person with mental illness. Each Australian state and territory also has an Act, Charter, or policy, concerning carer recognition. This legislation emphasises the tensions for families, referred to earlier, wherein there is now recognition of their needs in legislation, alongside the expectations of their primary caring responsibility for family members with mental illness.

Carers’ interests were further advanced when the Standing Council on Health (2012) revisited the Mental Health Statement of Rights and Responsibilities (Mental Health Consumer Outcomes Task Force, 1991) and added the right of carers to ‘receive services that assist them to provide care and support’ (Standing Council on Health, 2012, p. 19). They also highlighted the mutual responsibility of carers to:

Consider the opinions and skills of professional and other staff who provide assessment, individualised care planning, support, care, treatment, recovery and rehabilitation services to mental health consumers’ and to cooperate with these programs (Standing Council on Health, 2012, p. 20).

Support for carers

Numerous advocacy groups have, over many years, supported carers, for example, the Association of the Relatives and Friends of the Mentally Ill (ARAFMI) provides support and information for families and carers of people with mental illness, and the Schizophrenia
Fellowship of NSW, known as the Mental Illness Fellowship in other states, supports individuals and families whose lives are affected by mental illness through access to education, employment, housing, and strengthening of personal relationships. The influence of these advocacy groups has been reflected in successive parliamentary debates and policy documents (Henderson, 2005). Their representatives have made submissions to successive enquiries into mental health services (Commonwealth of Australia, 2006; HREOC, 1993).

**Participation of consumers and carers**

The first National Mental Health Plan (Australian Health Ministers, 1992b) had set out strategies for consumer input into mental health policy, building on the Mental Health Statement of Rights and Responsibilities (Mental Health Consumer Outcomes Task Force, 1991). Within the life of the Plan (1992-1997), the Commonwealth and each state and territory was to establish a ‘mental health consumer advisory committee which is representative of the range of mental health consumers and carers’ (Australian Health Ministers, 1992b, p. 13).

While representation of consumers increased in the first years of the national mental health strategy, approaches designed to meet the needs of carers were slower to develop, as noted above (NHMSESC, 1997). Carer groups had formed alliances with consumer groups, becoming their advocates, with their own needs as carers taking second place (National Mental Health Strategy Evaluation Steering Committee, 1997). Since then here has been a substantial increase in the number of mental health service organisations with structural arrangements for consumer participation in service delivery (Whiteford & Buckingham, 2005). However, there are fewer mechanisms for carer participation (Department of Health and Ageing, 2013).

Alongside the development of consumer advisory committees, the Mental Health Council of Australia (now Mental Health Australia (MHA)) was established in 1997 as a national body to represent mental health stakeholder organisations. It auspices the National Mental Health Consumer and Carer Forum (NMHCCF), which plays a key role in the development of mental health policy, and also initiated a national mental health leaders program for mental health consumer and carer leaders (Mental Health Australia, 2015).
**Recovery-oriented approach**

The second National Mental Health Policy (Australian Health Ministers, 2009) envisaged a mental health system that would promote recovery defined as:

A personal process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It involves the development of new meaning and purpose and a satisfying, hopeful and contributing life as the person grows beyond the effects of psychiatric disability. The process of recovery must be supported by individually-identified essential services and resources (Australian Health Ministers, 2009, p. 31).

A recovery approach was seen as relevant to all ages, across diagnoses and levels of severity. It was mainly ‘championed by the nongovernment community support sector and consumer advocacy bodies’ (Australian Health Ministers, 2009, p. 26). Recovery recognised lived experience and the role of consumers in sustainable interventions.

Standard 10.1: Supporting Recovery, in the revised National Standards for Mental Health Services (Mental Health Standing Committee, 2010) set out criteria for the inclusion of recovery principles in public and private mental health service provision, as did the Fourth National Mental Health Plan, 2009-2014 (Commonwealth of Australia, 2009b). In addition, informed by the lived experiences of people with mental illness, their families, and carers, two key documents offered guidelines for practitioners:


**National Framework for Recovery-oriented Mental Health Services: Policy and theory**

Informed by research and policy, the Framework explains the interconnections between personal and clinical recovery, and the importance of a client-centred focus and holistic approach.
National Framework for Recovery-oriented Mental Health Services: Guide for practitioners

This companion document provides detailed descriptions of five practice domains and their associated capabilities:

1. Culture and language of hope and optimism
2. Holistic and person-centred service provision
3. Personal recovery
4. Organisational commitment and workforce development
5. Social inclusion and the social determinants of health, and mental health and wellbeing.

It discusses the role of parenting in recovery, relationships between children and parents, and being responsive to children and young people of parents with a mental illness.

While recovery-oriented practices underpin mental health policy in many countries, Slade et al. (2014) noted that the transformation they require of mental health systems will not come easily and it is misleading to assume recovery is more important than, or can replace, effective medical treatment. They cited the findings of a systematic review (Leamy, Le Boutillier, Williams & Slade, 2011) which identified five key elements to recovery which comprises the CHIME framework:

- Connectedness
- Hope and optimism
- Identity
- Meaning and purpose
- Empowerment

Slade (2015) has observed that the recovery movement emerged from three narratives: the personal experience of people living with mental illness who want to tell their story; the discovery – from long-term epidemiological studies – that recovery is possible for more people than previously realised; and the narrative of identity politics where discrimination is challenged and people demand equality; this ‘is the first time that people directly affected by
mental health problems are themselves involved in the debate about their own future’ (Slade, 2015, p. 9). Byrne, Happell and Reid-Searl (2016) have advocated for lived experience practitioners as leaders of Recovery implementation in Australia, as they have their own internal experience and understandings of Recovery, and also understand the development of the lived experience movement.

Analysis of mental health reform to date

Until 1997, there was no information about the extent and impact of mental illness in Australia. Since then four national surveys of adults have been conducted, and two of children and adolescents (Lawrence et al., 2015; Sawyer et al., 2000). Analysis of the results of the 2007 National Survey of Mental Health and Wellbeing (Department of Health and Ageing, 2013) showed that, in the preceding year, 3.2 million adult individuals, 20% of the adult population, had experienced depression, anxiety, or substance use disorder.

Analysis of results of the 2010 Survey of People Living with Psychotic Illness (Department of Health and Ageing, 2013) found that 0.5% of the adult population, or 64,000 people, had been treated for a psychotic disorder in the preceding year. Each year 2,200 people commit suicide. This number has remained stable over the years (National Mental Health Commission, 2013). It was also found that 65% of people who meet the criteria for a mental disorder do not make use of mental health services (Department of Health and Ageing, 2013). This was attributed to structural, systems, and funding issues that continued to impede Australian mental health coverage. The complex, multilayered, fragmented Australian mental healthcare system is difficult for people to negotiate. It includes three tiers:

1. **Public-federal** with nine separate health systems and departments (one federal, eight state and territory) and also provides funding for primary healthcare through General Practitioners under the national medical and pharmaceutical benefits scheme. Further, the national unemployment scheme through Centrelink has a direct impact on people with mental illness and their families.
2. **Public-state** or territory governments have their own mental health policies and plans for acute care, hospitals, and community and disability services, as well as policy, education, the judiciary, and housing.

3. **Private health** includes large private, user-pays mental health services; for-profit and not-for-profit nongovernment community-managed mental health services (with government funding via contracts); and community-based family support services, which are also government funded (see Chapter 6).

This fragmented system with its ‘demarcation of responsibilities, militates against the formulation and implementation of holistic care for people with mental illness’ (Rosenberg, 2011, p. 13). The lack of coordination across the public mental health, social services, and financial support systems means people with mental illness have to negotiate a complex bureaucracy to get the services they need (Medibank Private Limited and Nous Group, 2013). The addition of private, for-profit, user-pays, and community-managed service providers further fragments the mental health service network (Bateman & Smith, 2011).

With increasing emphasis on primary healthcare, the federal government has become more involved in direct primary care initiatives. However, there is a limit to what can be done given mental health attracts just 7% of the total health budget even though mental illness constitutes 13.3% of the total disease burden and 25% of the non-fatal burden (Begg et al., 2007; Rosenberg, 2011). Although, with the reforms, mental health funding has far exceeded projected estimates, the costs of capital and consumer expenditure on private mental health services has not been included in these budget estimates (Medibank Private Limited and Nous Group, 2013).

While Australia is considered a world leader in mental health policy, funding has not backed expectations. Services to support deinstitutionalisation and enable people with mental illness to live fulfilling lives in the community are limited and exist in ‘impermeable government silos’ (Rosenberg, 2011, p. 17). This has been confirmed in reporting on the mental health reforms and services at the federal level provided through five key avenues (summarised in Table 5.4, p. 115):
### Table 5.3: National mental health policies and provisions for carers and families of people with mental illness 2010s

<table>
<thead>
<tr>
<th>2010s</th>
<th>Policy document</th>
<th>Description</th>
<th>Provision for carers and families</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>First National Primary Health Care Strategy Building a 21st Century Primary Health Care System (Department of Health and Ageing, 2010)</td>
<td>Primary health care strategy through Medicare Locals, now Primary Health Networks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Carer Recognition Act 2010 (Parliament of the Commonwealth of Australia, 2010)</td>
<td>Established a national legislative framework to increase recognition of carers in Australia; a carer was defined as an individual who provided personal care, support, and assistance to another individual who needed it due to a disability, medical condition, mental illness, or frailty</td>
<td>Referred throughout to carers, not families or family members. Schedule 1 specified the Statement for Australia’s Carers, listing rights and expectations</td>
</tr>
<tr>
<td></td>
<td>National Standards for Mental Health Services (Commonwealth of Australia, 2010)</td>
<td>Followed a review of the 1996 Standards, and included a standard relating specifically to carers, and to recovery (Standard 10.1, Supporting Recovery)</td>
<td>Standard 7: Specified the requirements of the mental health service to meet the rights and needs of carers. Families were not referred to or specified</td>
</tr>
<tr>
<td>2012</td>
<td>Roadmap for National Mental Health Reform, 2012-2022 (COAG, 2012)</td>
<td>Contained six priorities including: ‘promote person-centred approaches’ and improve the social and economic participation of people with mental illness</td>
<td>Performance indicators include: an increase in knowledge about mental illness; increased participation rates in education and employment by people with mental illness; increased participation in the labour force and the community by carers</td>
</tr>
<tr>
<td>2013</td>
<td>National Practice Standards for the Mental Health Workforce 2013 (Victorian Government Department of Health, 2013)</td>
<td>Followed a review of the 2002 Standards, which did not contain a Standard focusing on families</td>
<td>Standard 2: Working with people, families, and carers in recovery-focused ways emphasised the family context when a person has a mental illness</td>
</tr>
<tr>
<td></td>
<td>A National Framework for Recovery-oriented mental health services. Policy and Theory (Australian Health Ministers’ Advisory Council, 2013a)</td>
<td>A background paper that summarised research and policy, defined the concepts of recovery, and the role of self-determination</td>
<td>Family and carer relationships are important in the recovery process, including relationships between parents and their children</td>
</tr>
<tr>
<td></td>
<td>A National Framework for Recovery-oriented Mental Health Services. Guide for Practitioners and Providers (Australian Health Ministers’ Advisory Council, 2013b)</td>
<td>Sets out the five practice domains as a guide for all who work in mental health services, including consumer and family consultants, and the peer workforce</td>
<td>The recovery process for children and adults can be enhanced by their relationships with siblings and extended family members</td>
</tr>
</tbody>
</table>
1. *National Mental Health Strategy*: Since 1992, its progress has been tracked via 13 national mental health reports on Australian and state and territory government spending on, and employment participation rates for, people with mental illness (Department of Health and Ageing, 2013).


The Australian Institute of Health and Welfare (2013) has also reported annually on mental health services. A summary of these reports has been included in the mental health chapter of the *Report on Government Services* (Steering Committee for the Review of Government Service Provision, 2013).

**Mental health services in Australia**

As the discussion thus far shows, Australia has a complex, multilayered, fragmented Australian mental healthcare system and equally confusing funding arrangements. For the
period 2010-2011, when the present study was conducted, the Australian government expenditure on mental health services was $2.42 billion, with the Medicare Benefits Schedule comprising 12.4% of that amount, and the Pharmaceutical Benefits Scheme comprising 11.8% (Department of Health and Ageing, 2013). In the same period, direct expenditure on mental health services across all of Australia was $13.8 billion. This included expenditure by the federal, state, and territory governments, NGOs, private health insurers, consumers, and the corporate sector (Medibank Private Limited and Nous Group, 2013).

Spending by the major funders, the Australian Government, state and territory governments and private health insurers, constituted $6.9 billion (Department of Health and Ageing, 2013). The cost of direct non-health expenditures to support people with mental illness in the same period was reported to be $14.8 billion, and comprised income-support payments, insurance payments, non-income support and carer payments, and various services provided:

to people with mental illness, such as housing, education and training, and employment services (Medibank Private Limited and Nous Group, 2013). Expenditure on mental health services increased by 5.7% per Australian over the five years to 2010-2011 (AIHW, 2013).

Community-managed organisations (CMOs) receive funding from several sources to provide support with securing housing and accessing education and training, and employment. Responses to the NHWPRC (National Health Workforce Planning and Research Collaboration, 2011) survey from 268 CMOs showed that 58% had between two to five funding sources, with 35% receiving funding from state and territory health departments.

Before examining the services that absorb this funding, there follows a brief overview of the emergence of mental health services in Australia, the first of which was a government institution for the mentally ill, at that time called a lunatic asylum, which opened in New South Wales in 1811 (Happell, 2007). The treatment provided followed the British model, with the philosophy being one of humane care. Over time, overcrowding of asylums led to more custodial approaches. An Act of Parliament was passed in 1867 which made it mandatory that persons showing signs of mental impairment must be sent to a lunatic asylum rather than to prison (Keane, 1987, cited in Happell, 2007). By 1900 people experiencing mental illness
were separated from the ‘mentally retarded’ (Happell, 2007). The decades from the 1950s saw rapid changes in mental healthcare, most prominently deinstitutionalisation in the 1970s and 1980s, as already discussed (Happell, 2007).

About 100 years after the first government institution opened, services established by nongovernment organisations began to support people with mental illness in response to unmet community need (Bateman & Smith, 2011). While the history of these organisations has not been well-documented, it can be traced to the early 1900s, with the Lunacy Reform League championing the rights of the mentally ill and the Aftercare Association providing residential care to discharged psychiatric patients (Craze & Plant, 2008, cited in Community Mental Health Australia (CMHA, 2012).

The return of traumatised veterans following World War I saw the establishment of the NSW Association for Mental Health in 1932. In the 1940s and 1950s, other community organisations were established around Australia, along with peak bodies in the 1960s, 1970s, and 1980s arising from the need to coordinate the burgeoning community services in the wake of deinstitutionalisation (Craze & Plant, 2008). In 2007, Community Mental Health Australia (CMHA) was established as a coalition of the eight peak bodies of the state and territory community-managed mental health organisations, to promote leadership and direction and enhance the benefits of community-managed health and recovery services (CMHA, 2012).

Recognition of the need to care for children with a mental illness is a relatively recent phenomenon. While the term ‘child psychiatry’ was first used in 1899 (Manheimer, 1900), the parameters of child psychiatric diagnosis and treatment were only defined in 1933 (Eliasberg, 1964). The use of medication and residential treatment for children with behaviour problems was pioneered in the USA in the 1930s by Charles Bradley (Brown, 1998). Thereafter, psychiatric inpatient units and community treatment services for children and young people with mental health difficulties became a well-established part of the public mental health service system, supported by mental health services for children and young people provided by private practitioners.
### Table 5.4: Mental health reform policies and reviews

<table>
<thead>
<tr>
<th>National Mental Health Strategy</th>
<th>COAG policies</th>
<th>National Mental Health Reports</th>
<th>COAG progress reports</th>
<th>National Mental Health Commission reports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Third National Mental Health Plan, 2003</td>
<td></td>
<td></td>
<td>Fourth Progress Report covering implementation to 2009-10</td>
<td></td>
</tr>
<tr>
<td>Second National Mental Health Policy, 2008</td>
<td></td>
<td></td>
<td>Final progress report covering implementation 2010-11</td>
<td></td>
</tr>
<tr>
<td>Fourth National Mental Health Plan, 2009</td>
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</table>
The eight Australian states and territories are responsible for funding, provision, and administration of public mental health services, including hospitals providing specialist care for children and adults with severe mental illness (Department of Health and Ageing, 2013). The federal government manages mental health services subsidised by Medicare, the national healthcare program, with these services provided by General Practitioners, psychiatrists, and allied health providers, including social workers, psychologists, occupational therapists, and mental health nurses (Australian Institute of Health and Welfare (AIHW), 2012a).

Services for people with mental illness are provided according to severity of symptoms, and may include hospitalisation, medication, counselling, social intervention, and skills training, although, as already shown, to gain services they need to negotiate a complex network of care settings and service providers, including public, private, and nongovernment organisations. In 2011, there were 158 public and 49 private hospitals providing mental healthcare, as well as 161 residential facilities, 79 of which were government operated, and 1,082 community mental health care services (AIHW, 2013). State and territory specialist mental health services employed over 29,000 full-time equivalent (FTE) staff, with private hospitals employing 2,300 FTE staff in the same period. Medical practitioners subsidised by Medicare, and other health professionals providing services to people admitted to private hospitals, were not included in the AIHW (2013) review.

The number of community-managed organisations (CMOs) in Australia varies according to methods used to make these estimates, with 798 the number estimated by the National Health Workforce Planning and Research Collaboration (NHWPRC, 2011). In response to a survey of 268 CMOs conducted by the NHWPRC (2011), one-third of respondents stated they operated only in capital cities, and 19% operated in very remote areas. The CMOs reported that they were staffed by people with clinical, health, and other qualifications and relevant professional experience, although specific data about the composition of the CMO workforce is not routinely collected (AIHW, 2013). Volunteers were part of the workforce in 77% of the CMOs surveyed (NHWPRC, 2011).

Three categories of mental health CMOs have been identified: those providing only mental health specific programs (least frequent); some mental health specific programs in addition to other programs; and considerable mental health support services but no specific
mental health programs (most frequent) (Community Mental Health Australia, 2012). The CMOs reported four main types of provision: rehabilitation and support; therapeutic and clinical services; mental health education and public awareness; and co-morbidity programs (NHWPRC, 2011). Rehabilitation services and supports available to consumers included counselling, home-based outreach, advocacy services, family and carer support, leisure and recreation, healthcare and fitness, vocational training and employment support, accommodation support, respite, and peer support (Bateman & Smith, 2011). The strengths of CMOs lie in their capacity to support people with mental illness to connect to the community, and to available services, in meaningful ways (Bateman & Smith, 2011).

Private sector providers of mental health services include private hospitals, and medical and allied health professionals in private practice, referred to above. A substantial number of health professionals are employed in the private sector, and are funded through Medicare and other Australian Government sources, but data on these groups is not available (AIHW, 2013).

There are those who have been highly critical of the privatisation of mental health services as part of neoliberal welfare reform. For example, Sawyer (2005) attributed the increased administration – ‘close monitoring and regulation of … output’ (Sawyer, 2005, p. 290) – to the rise of managerialism and loss of professional autonomy and independence over treatment and care. In her opinion, documentation concerned performance measurement in terms of targets, inputs, outcomes, and indicators, ostensibly ‘designed to optimize accountability’ (Sawyer, 2011, p. 115). It was associated with increased regulation, administrative monitoring, and managerial supervision that had reshaped professional identities leading to stress and frustration, and the deskilling of professionals (Sawyer, 2011). Habibis (2005) dramatically declared the transformation of ‘the clinician into an administrator … [had] created a demoralised and dehumanised workplace’ (p. 308).

From Sawyer’s (2005) governance perspective, the actuarial risk regime and constant monitoring meant clinicians had to constantly ensure they were ‘covered’ (p. 291) in the event they needed to legally justify their decisions. She was particularly critical of constant risk assessment, which, she said, was not only about assessing potential client risk but also the threat of civil or medico-legal action against practitioners. Clinicians needed to be
increasingly mindful, therefore, that recordings of observations and information relating to the client could be used as evidence in a Court of Law (Sawyer, 2005).

As well as managerial governance, Henderson (2005) believed clients were expected to exercise self-governance through personal choice. They had to take responsibility for making socially responsible choices in maintaining and caring for themselves, while the state established the conditions for the exercise of personal choice and responsibility in the care of self and family (Henderson, 2005; Rose, 1993; Rose & Miller, 1992). Behind this rhetoric lay ‘compulsions surrounding the exercise of choice and an array of predefined and limited options for action’, with the ‘good consumer’ of healthcare being ‘compelled to make choices’, to exhibit appropriate ‘information-seeking’ behaviour, and to seek expert help, take the ‘right’ medication, and engage in personal risk management. Responsibility for health was placed with the individual (Henderson & Peterson, 2002, p. 3).

**Mental health policy in New South Wales**

There are parallels to the Australian processes in the development of policies and strategies in New South Wales over time, which can be seen in the increasing focus on consultation and partnerships, responses to the needs of families and carers, and the move to a recovery-oriented approach. This section discusses mental health policy and related initiatives in New South Wales (see Table 5.5, p. 124) and ends with a brief description of service provision in the regional locality in which the study was conducted.

**NSW Interagency Action Plan for Better Mental Health, 2005**

The NSW Interagency Action Plan for Better Mental Health (New South Wales Government, 2005) embraced the key principles of the National Mental Health Plan 2003-2008 (Australian Health Ministers, 2003). It emphasised a whole-of-government approach involving all sectors related to the management of mental health, including housing, welfare, community services, justice, and education. The NSW Action Plan did not refer to support services for carers or family members though it acknowledged that children might be affected by mental illness in the family.
A New Direction for Mental Health, 2006

A New Direction for Mental Health (New South Wales Department of Health, 2006) was a five-year plan aligned with the National Action Plan on Mental Health (COAG, 2006). It focused on promotion, prevention, and early intervention; integration in the mental healthcare system through partnerships with nongovernment agencies and consumers, carers, and families; increased participation of people living with mental illness in education, employment, and the community; and mental health workforce development. It made provision for funding education and community support for carers and families (NSW Department of Health, 2006).

NSW Mental Health Act, 2007

The NSW Mental Health Act 2007 (Parliament of New South Wales, 2007) repealed and replaced the 1990 Act (Parliament of New South Wales, 1990). The 2007 Act has been amended with explanations and revisions presented in an online guide (Mental Health Coordinating Council (MHCC), 2015). The most recent amendments in August 2015 removed the word ‘control’ from the Objects of the Act, replacing it with ‘recovery’. It states that a primary objective of the Act is to ‘to provide for the care and treatment of, and to promote the recovery of persons who are mentally ill or mentally disordered’ (MHCC, 2015, p. 1). The amended Act specifies that mental health facilities must consult with community agencies to ensure that services are provided to the person living with mental illness, as well as their primary carers and dependent children (s.79.2).

NSW Community Mental Health Strategy, 2008

The NSW Community Mental Health Strategy 2007-2012 (NSW Department of Health, 2008) emphasised a recovery-oriented approach to community mental health. The Strategy was informed by national policy documents, including the National Mental Health Policy (Australian Health Ministers, 1992a) and National Mental Health Plan 2003-2008 (Australian Health Ministers, 2003). It was supported by the NSW legislative framework, including the NSW Mental Health Act (Parliament of New South Wales, 2007). Strategies for the participation of consumers, families, and carers in the planning and delivery of services already in place were to be reviewed to achieve a consistent approach across New South
Wales’ mental health services. Support for families and carers provided through the Family and Carer Mental Health Support Program (New South Wales Department of Health, 2015) was also to be reviewed and replaced with a new program to be delivered through nongovernment agencies in all area health services in New South Wales.

**NSW Carers Action Plan, 2007**

The five-year NSW Carers Action Plan, 2007-2012 (NSW Department of Health, 2007a) was developed in response to a review of the 1999 NSW Government Carers Statement (New South Wales Department of Health, 2007b). It was designed to ensure recognition of, and support for, carers of people who have frailties, disabilities, mental illness, drug dependence, and terminal or chronic illness. Support for carers included information about benefits and entitlements, counselling, respite, and services. The Carers Action Plan acknowledged the educational and recreational needs of young people with caring responsibilities for their parent.

**NSW Children of Parents with a Mental Illness (COPMI) Framework for Mental Health Services, 2010**

The New South Wales COPMI Framework for Mental Health Services, 2010-2015 (New South Wales Department of Health, 2010) aligned with earlier national and NSW state initiatives, such as the Principles and Actions for Services and People Working with Children of Parents with a Mental Illness (Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA), 2004) and NSW New Direction for Mental Health (New South Wales Department of Health, 2006). The key strategies of the COPMI Framework were the prevention of mental illness for infants, children, and young people, where parents or family members had a mental illness; provision of responsive services; and development of service providers’ capacity to recognise, respond to, and provide family-focused services, while acknowledging the diversity of family needs.

**NSW Carers (Recognition) Act, 2010**

The New South Wales Carers (Recognition) Act 2010 (Parliament of New South Wales, 2010) provided legislative acknowledgement of the carers’ contribution to the community and people in their care, including people with disabilities, terminal or chronic illness, and mental
illness, as well as frail or aged individuals. Carers included those who provided ongoing personal care, support, and assistance to the person needing care. Family members were not automatically recognised as carers, reflecting the national Carer Recognition Act (Parliament of the Commonwealth of Australia, 2010). The New South Wales Carers Charter contained in the Act acknowledged that children and young people might be carers and should be supported.

**Living Well: Putting People at the Centre of Mental Health Reform in NSW, 2014**

The two ‘Living Well’ (New South Wales Mental Health Commission, 2014a, 2014b) documents were prepared by the NSW Mental Health Commission, established under the Mental Health Commission Act 2012 (Parliament of New South Wales, 2012). The documents set an agenda for mental health reform in New South Wales. Putting People at the Centre of Mental Health Reform in NSW (NSW Mental Health Commission, 2014a) briefly charted the history of the reform process in NSW, acknowledging the influence of successive enquiries into mental health services, as well as developments in other Australian states and other countries. It provided a review of the prevalence of mental illness in NSW; expenditure on mental health services, and factors influencing and associated with mental health (or illness), such as employment and homelessness, and flagged new approaches to care. The lived experiences of people with mental illness and family members and carers were mentioned throughout as was the role of the consumer movement in reform.

**Living Well: A Strategic Plan for Mental Health in NSW, 2014**

Living Well: A Strategic Plan for Mental Health in NSW, 2014-2024 (New South Wales Mental Health Commission, 2014b) aimed to promote mental health and wellbeing, better integration of care, coordinated responses, and increased consumer and carer participation at all levels. It recognised the role of families and carers in contributing to a person’s recovery, and the needs of families and carers for information about mental illness, and their difficulties in accessing services for their family member. Recovery was a key value of the reform process. However, the Plan acknowledged that, while, ideally, autonomous individuals would determine their own path to recovery, ‘development processes for legislation and policy can create barriers to recovery’ and consultation processes among government agencies and
stakeholders could lead to the ‘voices of people with mental illness [being] easily lost’ (NSW Mental Health Commission, 2014b, p. 49).

**NSW Carers Strategy, 2014**

The New South Wales Department of Family and Community Services (2014) estimated that there were 857,000 carers in New South Wales, and that carers in Australia contributed $40 billion in the unpaid hours of care they provided. The New South Wales Carers Strategy 2014-2019 (New South Wales Department of Family and Community Services, 2014), which followed consultation with over 2,000 carers, has five focus areas: (i) improving opportunities for carers to participate in paid work, such as increasing workplace flexibility, and supporting young carers to complete school; (ii) improving service design so that carers could look after their own wellbeing; (iii) making information readily available and accessible to carers; (iv) increasing the involvement of carers in service delivery; and (v) using data and research to create evidence to inform carer policies and programs. The shift to greater recognition of and support for families and carers set out in this Carers Strategy aligned with the national policies.

**NSW Family and Carer Mental Health Support Program, 2015**

The New South Wales Family and Carer Mental Health Support Program (New South Wales Department of Health, 2015) requires the development of partnerships between the NGO providing the family and carer support program, and the families and carers, the local health district, and other NGOs working with families. Five nongovernment organisations provide support to families and carers where a family member has a mental illness across New South Wales: CentaCare, Carer Assist, Uniting Care Mental Health, Mission Australia, and Aftercare. Support includes education about mental illness, support, and advocacy, and support to develop peer support groups.

**Mental health services in New South Wales**

Government spending on mental health services in New South Wales in 2010-2011 totalled AUD1.3 billion; community mental health services accounted for 44% of this. In comparison, the total expenditure in Victoria, the second largest state by population, for the same period
was AUD974 million, with community mental health services accounting for 66%. Nongovernment agencies in NSW received 6% of the total expenditure in that state, compared with 12.8% in Victoria (Department of Health and Ageing, 2013). Table 5.6 (p. 125) shows the proportion of the Australian population in each state or territory (Australian Bureau of Statistics, 2015), and compares the expenditure on mental health services overall, the proportion of that total spent on community mental health, and nongovernment organisations, and compares the proportions of each population seen by Medicare subsidised providers (Department of Health and Ageing, 2013). The comparisons highlight differences in the mix of services such as variations in funding to nongovernment organisations, and similarities such as the proportion of each population seen by psychiatrists, GP’s and allied health providers.

Public mental health services in New South Wales are delivered through 15 Local Health Districts, each managed by a Board. The present study was conducted in the Hunter New England Local Health District (LHD). The Hunter area lies to the north of Sydney, and the LHD has seven mental health services, covering 25 local council areas, which respond to the needs of children and young people, adults up to the age of 65 years, and older people. Mental health services include psychiatric emergency care, intensive, acute, and longer-term hospital care, and long-term care for people unable to live in the community. Intake criteria, such as acuity of symptoms, or risk of self-harm or harm to others determines admission to these services. Where an individual does not meet these intake criteria, services are available through nongovernment agencies and private practitioners.

Support for families living with, or caring for, a family member with mental illness is provided by clinicians in public mental health services (New South Wales Department of Health, 2013) and the five nongovernment organisations referred to above. The New South Wales Carers Strategy (New South Wales Department of Family and Community Services, 2014) has set as priorities the creation of opportunities for carers to participate in employment, and young people who have caring roles to complete their education. Support for family members and carers is also available through nongovernment organisations.
<table>
<thead>
<tr>
<th>Year</th>
<th>Policy</th>
<th>Description</th>
<th>Provision for carers and families</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>NSW Interagency Action Plan for Better Mental Health (NSW Government, 2005)</td>
<td>NSW whole-of-government approach to mental health service delivery</td>
<td>No reference to the needs of carers or family members. Acknowledges that children may be affected by mental illness in the family</td>
</tr>
<tr>
<td>2007</td>
<td>NSW Mental Health Act 2007 (Parliament of New South Wales, 2007)</td>
<td>Legislation under which people diagnosed with mental illnesses are treated and supported to recovery</td>
<td>Specifies the legislative requirements of services for the involvement of primary carers, who may be a family member</td>
</tr>
<tr>
<td></td>
<td>NSW Community Mental Health Strategy 2007-2012 (NSW Department of Health, 2008)</td>
<td>Takes a recovery focus, and advocates for community participation, and involvement of consumers, families and carers</td>
<td>Sets out the strategies for the Family and Carer Mental Health (2005) program, including partnerships with consumers, carers and families</td>
</tr>
<tr>
<td></td>
<td>NSW Carers Action Plan 2007-2012 (NSW Department of Health, 2007)</td>
<td>A five-year Plan aimed at supporting carers, in the context of partnerships between NSW Health and other policy areas</td>
<td>Focused on all carers (including people caring for someone with mental illness) vis-à-vis access to support and respite</td>
</tr>
<tr>
<td>2010</td>
<td>NSW Children of Parents with a Mental Illness (COPMI) Framework for Mental Health Services 2010-2015 (NSW Department of Health, 2010)</td>
<td>Sets out strategic directions for NSW area mental health services and NSW health partners to foster and improve the mental health and wellbeing of children and young people in NSW who have a parent with a mental illness</td>
<td>Acknowledges that children and young people may have a caregiving role for their parent or parents</td>
</tr>
<tr>
<td>2010</td>
<td>NSW Carers (Recognition) Act 2010 (Parliament of New South Wales, 2010)</td>
<td>Legislation aimed at recognising the role and contribution of carers to the community and to the people they care for</td>
<td>Defines carer, including those caring for people with mental illness, and sets out carer’s rights</td>
</tr>
<tr>
<td>2014</td>
<td>Living Well. Putting People at the Centre of Mental Health Reform in NSW: A Report (NSW Mental Health Commission, 2014)</td>
<td>A report based on the perspectives of people living with mental illness in NSW. A companion document to the 2014 Plan below</td>
<td>Includes personal accounts of people living with mental illness as consumers and carers</td>
</tr>
<tr>
<td></td>
<td>Living Well: A Strategic Plan for Mental Health in NSW, 2014-2024 (NSW Mental Health Commission, 2014)</td>
<td>A companion to the 2014 Report, sets out directions for mental health reform in NSW over the next 10 years</td>
<td>Acknowledges the difficulties families and carers have in navigating the mental health system, and the need for support and information about service access</td>
</tr>
<tr>
<td></td>
<td>NSW Carers Strategy 2014-2019 (NSW Department of Family and Community Services, 2014)</td>
<td>A five-year plan aimed at improving the position of carers in New South Wales</td>
<td>Acknowledges the role and diversity of carers, including those caring for someone with a mental illness, including young carers</td>
</tr>
<tr>
<td>2015</td>
<td>NSW Family and Carer Mental Health Support Program (NSW Department of Health, 2015)</td>
<td>Support for families and carers through enhanced skills of mental health workers and access to support programs for families</td>
<td>A framework for mental health services and nongovernment agency provision of support to carers and families</td>
</tr>
</tbody>
</table>
Table 5.6: Spending on Australian mental health services, 2010-2011

<table>
<thead>
<tr>
<th>States and territories of Australia</th>
<th>% of Australian population</th>
<th>Spending on Mental health ($millions)</th>
<th>Community mental health % of total service expenditure</th>
<th>NGOs % of total service expenditure</th>
<th>% population seen by Medicare subsidised providers (Psychiatrists, GPs, allied health)</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>31.99</td>
<td>1.303</td>
<td>44</td>
<td>6.0</td>
<td>7.0</td>
</tr>
<tr>
<td>Victoria</td>
<td>24.87</td>
<td>947</td>
<td>66</td>
<td>12.8</td>
<td>7.7</td>
</tr>
<tr>
<td>Queensland</td>
<td>20.10</td>
<td>830</td>
<td>56</td>
<td>8.5</td>
<td>6.6</td>
</tr>
<tr>
<td>Western Australia</td>
<td>10.98</td>
<td>523</td>
<td>53</td>
<td>8.7</td>
<td>5.6</td>
</tr>
<tr>
<td>South Australia</td>
<td>7.16</td>
<td>327</td>
<td>56</td>
<td>11.5</td>
<td>6.9</td>
</tr>
<tr>
<td>Tasmania</td>
<td>2.18</td>
<td>116</td>
<td>59</td>
<td>13.5</td>
<td>6.1</td>
</tr>
<tr>
<td>ACT</td>
<td>1.64</td>
<td>72</td>
<td>73</td>
<td>17.3</td>
<td>5.6</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1.04</td>
<td>43</td>
<td>64</td>
<td>12.1</td>
<td>2.9</td>
</tr>
</tbody>
</table>

Conclusion

Despite successive policies and evaluation reports, and millions of dollars spent annually on mental health services, the number of people with mental illness has not decreased and many service gaps remain (Rosenberg, 2011; Whiteford & Buckingham, 2005). People with mental illness, such as participants in the present study, become embroiled in a complex and fragmented network of federal, state, territory, and private services. The 2011 ministerial statement outlining the 2011-2012 budget for mental health reform concluded:

Despite previous attempts at reform and investment by governments, too many people with severe and debilitating mental illness are still not getting the support they need, don’t know where to find it, and are falling through the cracks in the system. The
families and people who care for them struggle with a system which often causes them frustration and even despair (Australian Government, 2011, p. 12).

Hence the Australian Government’s (Department of Health, 2015) response to Contributing Lives, Thriving Communities: Review of Mental Health Programmes and Services (National Mental Health Commission, 2014) is designed to remove service fragmentation and provide integrated and coordinated care at a local level, based on individual need. The proposed stepped-care approach plans to progress from early intervention and prevention, such as programs in schools, to wrap-around services for people with complex needs.

The chapter provided an account of the changing legislative and policy framework for mental health reform in Australia, including provisions for consumers and carers who have been influential in the changes to service delivery and the increased recognition of the role of people with lived experience in policy, service provision, and research. It also provided a brief overview of mental health services before examining mental health policy in New South Wales, the context in which this study was conducted. It showed that, despite mental health reform, however, support services were not funded in proportion to the increasing number of Australians living with mental illness. The following chapter discusses the policies relating to family support services for families living with mental illness.
Chapter 6

Family support: Policy and service context

Chapter 5 discussed mental health policy and services. The focus of this chapter is family support for families with children who need support, regardless of the health or mental health issues affecting the family. In this study, the term ‘family support’ refers to community based services that offer support and guidance to parents with children to maintain the family unit and enable them to meet their own needs. Parents and children may, or may not, have a diagnosed or undiagnosed mental illness. As with mental health, family support policy is managed by the Federal government in tandem with associated policies in each state or territory. For example, the Commonwealth Department of Social Services (DSS) administers certain policies concerning family and parenting support such as family and relationship services, prevention and early intervention services, and community playgroups (Department of Families Housing Community Services and Indigenous Affairs, 2012), with similar state and territory departments administering policies relating to child protection and related support services in each of those jurisdictions. This Commonwealth and state/territory bureaucratic structure may mean, for example, that a family applies for, and is subsequently accountable to, a Commonwealth income-support agency for regular welfare payments. However, they may also need to access income support or other services from an agency administered by the relevant state department, or nongovernment agency. Differing eligibility criteria may apply, with a parent having to negotiate several bureaucracies to gain their entitlements. The chapter begins by describing the development of family support services in Australia and continues with an outline of the family support service context, which includes the family support agency under study. It presents a summary of family support program arrangements in Australia and the state of New South Wales where this study was conducted. It uses an ecological model, shown in Figure 6.1 in which families – the ‘case’ being studied – sit at the centre surrounded by services, attendant policies, and prevailing values and attitudes. These broader social factors exerted a major influence on the way in which the
Family Support Newcastle centre developed and administered the Headin’ Up program from which the families who participated in this study were drawn. The family support program was a New South Wales state initiative within a network of Federal and state funding, policies, and services.

Figure 6.1: An ecosystem representation of the families in this study

Family support services in Australia

Wolcott (1989) observed that, in Australia, family support is both an approach and ‘specific type of service’ (p. 7) that has generally been linked with child welfare services. Its goal is to ‘maintain family unity by providing a range of generic and specialist services to families to strengthen their own capacity to meet their needs’ (Wolcott, 1989, p. 7). Most family support services in Australia are provided by nongovernment, not-for-profit child and family and community welfare agencies with funding from government and other sources.
‘Family support’ services internationally began in the 19th century as a response to the growing problem of child abandonment, illegitimacy, abuse, and neglect. These problems were seen as a product of a system where children were regarded as the property of their parents, who could treat them in any way they saw fit. Charitable and philanthropic endeavours saw the ‘first wave’ of the child rescue movement in North America and the United Kingdom in 1874 and 1884 respectively (Lamont & Bromfield, 2010).

In Australia, however, the need to protect children began 100 years earlier with the arrival of the First Fleet in 1788, which brought orphaned and convict children who were ‘boarded out’ with approved families, or placed in orphanages (Liddell, 1993; Tomison, 2001). The growing population and gold rush in the mid-1800s led to an increase in the number of children left abandoned or destitute, at a time when orphanages were the main means of child welfare provision (Tomison, 2001). However, the conditions in, and the cost of, institutional care, administrative expediency, and evolving child development theory led to the ‘boarding out’ of children, an early form of foster care. While some church-based agencies continued to provide institutional care, boarding out in New South Wales was managed under the State Children’s Relief Act 1881; South Australia, Victoria, and Tasmania followed suit at around the same time (Australian Catholic Social Welfare Commission, 1997).

Developments in North America and the United Kingdom paved the way for the establishment of nongovernment or voluntary child welfare societies in Australia, with the first being established in New South Wales, Victoria, and Western Australia. By the end of the 19th century, most states had established Children’s Courts, and had legislation in place to protect children from abuse and neglect (Lamont & Bromfield, 2010). State rather than Federal responsibility for child protection has continued since that time.

The focus shifted from the child to the family around the early 20th century with emphasis being placed on the effect of the child’s environment on his or her development. This led to the establishment of child welfare departments and the introduction of financial support to mothers so they could raise their children themselves: ‘Regulation of childhood began to take place within families, rather than without’ (van Krieken, 1991, p. 138).
Federal government involvement in some areas of social welfare in Australia began in the 1940s, in part, with recognition of the need to reduce poverty following the Great Depression and high unemployment in the aftermath of the First World War. The 1940s were preceded by the Labor Governments of Curtin and Chifley, which spanned eight years, and saw the introduction of the first measures to reduce poverty-related child abuse and neglect (Fogarty, 2008). These included unemployment benefits, maternity allowances, a child endowment payment, and widow’s pension. The care and protection of children became family focused so that children could remain with, rather than being removed from, their parents.

The late 1960s and early 1970s saw yet another shift in focus from individual pathology to the structural causes of disadvantage. Support was provided to relieve economic pressures, empower families through parenting skills training and community development, and keep families together (Fogarty, 2008). The election of the Whitlam Labour Government in Australia in 1972 brought increased Federal Government involvement in welfare, health, and education. There was a greater emphasis on support for children and families and a wave of optimism about the benefits of redistributive programs to alleviate poverty. However, recession, inflation, and unemployment in the 1970s brought budget pressures and the premature ousting of the Whitlam government. The subsequent Fraser Liberal Government, elected in 1975, dealt with the fiscal crisis by reducing the role of the Federal Government in welfare provision (Australian Catholic Social Welfare Commission, 1997). At the same time, the clinical literature raised awareness about the negative aspects of removing children from their families, particularly where children were repeatedly moved from one carer to another (Liddell, 1993).

In 1978, the Family Support Service Scheme (which became the Family Support Program) was established within the Commonwealth Office of Child Care (Wolcott, 1989). It provided ‘community-based services for families with young children who were experiencing stress … helping to develop a natural network of support, referral and self-help services’ (Wolcott, 1989, p. 8). The Program provided funds to ‘support and complement existing family welfare structures’ (Office of Child Care, 1984, cited in Wolcott, 1989, p. 8). The Commonwealth concluded its involvement in the Family Support Program ten years later,
leaving each state or territory to make decisions about programs to be funded from Commonwealth general revenue. The Commonwealth, however, continued to provide income and family support payments, and some aspects of support for families (Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSI), 2012).

In 2009, the Federal government announced the establishment of a reconfigured Family Support Program (FSP) designed to integrate family, child, and parenting services. It was lauded as an opportunity for the community sector and government to collaborate in the provision of coordinated and flexible support to vulnerable families (Australian National Audit Office, 2011). This coincided with the publication of the National Framework for Protecting Australia’s Children 2009-2020 (Commonwealth of Australia, 2009c). It advocated collaboration between Federal, state, and territory governments in order to protect children. The Commonwealth framework was intended to complement the child protection systems managed by the state and territory governments.

In 2012, FaHCSIA published a discussion paper addressing the Families and Children’s Services Stream of the Family Support Program (FSP) and invited submissions from the family welfare sector (Department of Families, Housing, Community Services and Indigenous Affairs, 2012). Subsequently, FSP guidelines for organisations applying for funds were published, accompanied by a framework setting out the program objectives and performance indicators. The success of the FSP would be measured by the extent to which targets – to be provided as proportions and numbers – had been met (Department of Social Services (DSS), 2011). Nongovernment organisations providing family support services in the context of child protection in each state and territory could also provide components of the DSS Family Support Program. Table 6.1 provides a snapshot of Government welfare reforms since the 1940s generally, with a glimpse into the context of child and family support in particular. In Australia, the Federal and state and territory governments participate in the administration and funding of family support services, with nongovernment agencies generally providing the services under contracted arrangements with government departments. The broad aims of the programs are to support families to strengthen their capacity to meet their needs. In addition to the child and family services programs the Federal
government administers a mental health support program for families, and children and young people.

**Australian Government family support program**

As shown in Table 6.2 (p. 136) there are two support streams for families living with mental illness run by two separate federal government departments as follows:

1. Family and Children’s Services (Department of Families, Housing, Community Services and Indigenous Affairs, 2013).
2. Family Mental Health Support Service (Department of Social Services, 2012).

**Family and Children’s Services**

The term ‘family support’ in national policy denotes Australian Federal government support for families in targeted groups through the Department of Social Services (previously Families Housing, Community Services, and Indigenous Affairs).

In 2009, a national Family Support Program was announced (Australian National Audit Office, 2011). It brought together existing family, children’s, and parenting services operating at a national level.

In November 2010, reforms to this program were announced, with two streams, the Family and Children’s Services and the Family Law Services, implemented in July 2011 (Department of Families Housing Community Services and Indigenous Affairs, 2011). The Family and Children’s Services programs targeted vulnerable families through better service coordination and greater flexibility for service providers (Department of Families, Housing, Community Services and Indigenous Affairs, 2013). Family and Children’s Services comprise four support programs:
Table 6.1: Policy changes in mental health and family support (1940s-present)

<table>
<thead>
<tr>
<th>Federal Government in office</th>
<th>Reforms to welfare</th>
<th>Changes in policy directions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mental health</td>
</tr>
<tr>
<td>Labor 1940s</td>
<td>Introduction of unemployment and sickness benefits, maternity allowance, and funeral and health benefits</td>
<td>Institutionalisation of severely mentally ill</td>
</tr>
<tr>
<td>Coalition (Liberal Party and Country Party) 1950s-1960s</td>
<td>Decrease in welfare spending</td>
<td>Deinstitutionalisation begins in late 1960s</td>
</tr>
<tr>
<td>Labor 1972-1975</td>
<td>Increase in welfare, health, and education spending; and creation of supporting mother’s benefit</td>
<td></td>
</tr>
<tr>
<td>Coalition (Liberal Party and Country Party) 1975-1983</td>
<td>Increased welfare costs led to reduction of healthcare funding and shift of</td>
<td>By late 1980s, families of people with mental illness had been constructed as carers, and incorporated into mental health policy (see Chapter 5)</td>
</tr>
</tbody>
</table>

1907 - Harvester Judgement - the setting of a fair living wage
1908 – Invalid and Old Age Pension Act introduced
The First World War 1914-1918; the Great Depression; high unemployment

The first three decades of the 20th century – beginnings of the Australian welfare system
<table>
<thead>
<tr>
<th><strong>Responsibility from government to the individual</strong></th>
<th><strong>Introduction of economic rationalism (neoliberalism)</strong></th>
<th><strong>Mid-1980s: Federal government withdraws from direct provision of family support services, which became a State responsibility</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Supplement introduced to replace a universal income supplement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Work preparation programs introduced for sole parents</td>
<td></td>
</tr>
<tr>
<td><strong>Coalition (Liberal Party and Country Party) 1996-2007</strong></td>
<td>Work-for-the-dole introduced under the mutual obligation policy</td>
<td>Second Mental Health Plan (1998-2003) with quality control measures and benchmarks introduced</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Third Mental Health Plan (2003-2008) with further emphasis on measurement and ratings</td>
</tr>
<tr>
<td><strong>Labor 2007-2013</strong></td>
<td>Introduced paid parental leave; disability care, improved pay of low-income workers, among other initiatives</td>
<td>Fourth Mental Health Plan (2009-2014) introduced employment participation rates for mentally ill and transferred support role to families with a mentally ill family member</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2009: Reconfigured Federal Family Support Program (FSP) to integrate federally funded services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2012: Continuation of FSP, targeting the most vulnerable families</td>
</tr>
<tr>
<td><strong>Coalition (Liberal Party and Country Party) 2013 to present</strong></td>
<td>Introduction of discretionary fee for most patients to see General Practitioner</td>
<td>Additional funds for adolescent mental health services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Means testing for childcare</td>
</tr>
</tbody>
</table>

Adapted from Green (2002)
1. **Communities for Children (C4C):** This is a brokering service for families with children up to 12 years delivered by local organisations, including home visiting, early learning and literacy, parenting and family support. Activity in each C4C location is guided by a local Committee.

2. **Family counselling services** for couples and families going through separation or divorce are provided by Approved Family Counselling Organisations under the Family Law Amendment (Shared Parental Responsibility) Act 2006. (Parliament of Australia, 2006).

3. **Specialist services** for families who are vulnerable though drug use, violence, and trauma, including Kids in Focus (family drug support), Family Relationship Services for Humanitarian Entrants, and Specialised Family Violence Services.

4. **Community playgroups** are informal gatherings for parents and caregivers with children under school age; they provide opportunities for social and supportive networking for parents, and for children’s social and emotional development.

**Family Mental Health Support Service (FMHSS)**

The first FMHSS (Department of Families, Community Services and Indigenous Affairs, 2007) replaced the Mental Health Community Based Program. It aimed to empower and strengthen families through information, education and skills development; develop more effective parenting, relationships and communication strategies employed within families affected by mental illness; provide enhanced support for children of parents with a mental illness; improve the emotional health and wellbeing of family members and carers; and improve family functioning and social support for families, carers, children, and young people affected by mental illness. The FMHSS was one component of the Targeted Community Care (Mental Health) Program (Department of Social Services, 2012):

1. **Family Mental Health Support Service (FMHSS)** targets children and families living with a family member with mental illness. It includes early intervention to vulnerable families with children who are at risk of, or affected by, mental illness and flexible, responsive options for children and young people up to the age of 18 years affected by, or at risk of, mental illness, and their families.
2. *Mental Health Respite*: Carer support to assist carers of people with mental illness or disability to sustain their caring role and maintain connections with the communities by increasing access to flexible, innovative carer support services.

3. *Personal Helpers and Mentors Program* provides increased opportunities for recovery for people aged 16 years and over whose lives are severely affected by mental illness and helps participants to overcome social isolation and increase their connections to the community.

Table 6.2: Australian Government support programs for families

<table>
<thead>
<tr>
<th>Family and Children’s Services</th>
<th>Targeted Community Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core stream</td>
<td>Program</td>
</tr>
<tr>
<td>Communities for Children (C4C)</td>
<td>Family Mental Health Support Service</td>
</tr>
<tr>
<td>For couples and families going through separation or divorce</td>
<td>Mental health respite: Carer support</td>
</tr>
<tr>
<td>Services for families who are vulnerable though drug use, violence, and trauma,</td>
<td>Personal Helpers and Mentors</td>
</tr>
<tr>
<td>Informal gatherings for parents and caregivers with children under school age</td>
<td></td>
</tr>
</tbody>
</table>

**New South Wales family support system**

Historically, mental health services were provided by government but, with welfare reform, this changed to a sharing of responsibility between government, communities, and families.
In New South Wales support to families with children is provided by government and nongovernment agencies. As shown in Table 6.3, (p. 139) it has three distinct arms:

2. Early intervention (Department of Premier and Cabinet, 2009).

**Child protection**

Child protection in New South Wales is governed by the Children and Young Persons (Care and Protection) Act (Parliament of New South Wales, 1998) that provides for parents and others responsible for children and young people in their care and the Community Welfare Act (Parliament of New South Wales, 1987) to promote, maintain, and improve the wellbeing of the people of NSW through services offered in collaboration with community welfare organisations. The state government Department of Family and Community Services is responsible for state child protection legislation and services (Department of Premier and Cabinet, 2009). They involve receiving and responding to notifications of children at risk of significant harm.

**Early intervention**

Nongovernment agencies are contracted to deliver early intervention and prevention services, such as the Family Mental Health Support Service. The Department of Premier and Cabinet (2009) introduced the whole-of-government *Keep Them Safe* approach to child safety and wellbeing in New South Wales as a response to the Report of the Special Commission of Inquiry into Child Protection Services in New South Wales (Wood, 2008). It requires mandatory reporting of suspected child abuse and neglect by those who work with children, such as health workers, teachers, police, and others, or those in related management positions, and programs. It includes the following:

- *Family Referral Services* for families where child protection intervention is not required, but who would benefit from supportive services.
- **Safe Start**, which identifies and supports women and families with social and emotional issues during pregnancy and following birth, and focuses on mental health issues and their possible impact on the parenting role.

- **Brighter Futures** is an early intervention program designed to build the resilience of vulnerable families with children aged up to nine years of age.

- **Sustaining NSW Families** offers intensive, structured home-visiting during pregnancy and infancy for vulnerable families undergoing socioeconomic disadvantage, and experiencing associated psychosocial distress.

- **Aboriginal Intensive Family Support Services** offer time-limited, home-based support for families where Indigenous children or young people are at risk of entering out-of-home care (see Table 6.3).

- **Families NSW** is a specific New South Wales population-based early-intervention program for families expecting a baby or with children of up to the age of eight years (Families NSW, n.d.). It is provided jointly by three government departments (Education and Training, Family and Community Services, and Health). The program’s website provides links to resources to support parents with infants, toddlers, and young children, such as playgroups and parenting programs.
Table 6.3: NSW family support system

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child protection</td>
<td>This is regulated by the Children and Young Persons (Care and Protection) Act (Parliament of New South Wales, 1998) and the Community Welfare Act (Parliament of New South Wales, 1987)</td>
</tr>
<tr>
<td>Early intervention</td>
<td>Involves a range of services offered through Keep Them Safe: A Shared Approach to Child Wellbeing (Department of Premier and Cabinet, 2009):</td>
</tr>
<tr>
<td></td>
<td>- Family Referral Service</td>
</tr>
<tr>
<td></td>
<td>- Safe Start</td>
</tr>
<tr>
<td></td>
<td>- Brighter Futures</td>
</tr>
<tr>
<td></td>
<td>- Sustaining NSW Families</td>
</tr>
<tr>
<td></td>
<td>- Aboriginal Intensive Family Support Services</td>
</tr>
<tr>
<td></td>
<td>Families NSW (n.d.) is a specific early-intervention support program.</td>
</tr>
<tr>
<td>Family support</td>
<td>Family support is generally offered by NGOs in partnership with government.</td>
</tr>
</tbody>
</table>

Family support

Family support services have always been community based. They are generally offered by autonomous nongovernment organisations that work collaboratively with government and other community-based agencies to support children and families. They receive government funds to deliver contracted services and operate programs with other sources of funding. They provide one or more of the services shown in Table 6.3. In NSW there are least 20 peak bodies that advocate for child and family wellbeing (New South Wales Department of Family and Community Services, n.d.). The peak body for family support services in New South Wales is NSW Family Services Inc. It defines its role as supporting family services in NSW by providing advice and information about policy and reform, and up-to-date research on which to base practice (New South Wales Family Services Inc., 2014).
Mental health family support services for families in New South Wales

As discussed above, the origins of family support services lay in a shift in focus from the child to the family early in the 20th century, and a refocus in the 1970s from individual pathology to the structural causes of disadvantage (van Krieken, 1991). This continued to involve the strengthening and development of communities in which families lived. The agencies providing services to families were located in the community and managed by local management committees, or were autonomous nongovernment agency programs providing a range of services, including family support.

Treatment for people with a mental illness also saw significant changes from care in large institutions to care in the community. This required active involvement of families as carers, a role for which they were ill-equipped. Hence, a parallel service sector developed over the last 30 years to educate and support carers and families of people with a mental illness. Table 6.4 provides a summary of services to families with children, and to families living with a family member with mental illness, provided by government and nongovernment organisations in New South Wales.

Table 6.4: NSW family support services and mental health services for families

<table>
<thead>
<tr>
<th>Sector</th>
<th>Mental health family support services</th>
</tr>
</thead>
</table>
| **Government**  | *NSW Department of Family and Community Services*  
Child protection services in terms of the Children and Young Persons (Care and Protection) Act (Parliament of New South Wales, 1998) and Community Welfare Act (Parliament of New South Wales, 1987)  
Support for carers in terms of the NSW Carers Strategy 2014-2019 (New South Wales Department of Family and Community Services, 2014)  
*NSW Department of Health*  
Family Friendly Mental Health Services  
Family and Carer Mental Health Support Program |
| **Nongovernment** | Education, training, support, advocacy, peer support, and recovery e.g., ARAFMI (Association of Relatives and Friends of the Mentally Ill), the Schizophrenia Fellowship of NSW, and Family Support Newcastle. |
Government services

**NSW Department of Family and Community Services**

This department offers statutory child protection interventions and related services funded to perform the ‘functions of government that receive and assess allegations of child abuse and neglect, and/or harm to children and young people, provide and refer clients to family support and other relevant services, and intervene to protect children’ (Steering Committee for the Review of Government Service Provision, 2010, p. 15, cited in Bromfield, Holzer & Lamont, 2010).

It also delivers the NSW Carers Strategy 2014-2019 (New South Wales Department of Family and Community Services, 2014) based on carers’ rights to choices and opportunities to participate in paid work; good health and wellbeing; information; participation in decisions affecting them and the people they care for; and evidence-based policy and practice. Above all, the lived experience of carers must be validated.

**Department of Health**

This department offers Family Friendly Mental Health Services through which clinicians:

- Consider the family and carer network supporting the consumer, and support consumers to involve families and carers appropriately.
- Provide information to families and carers about mental illnesses and the mental health system.
- Recognise the changing needs of families and carers and help them access support, education, advocacy
- Ensure their personal and organisational values serve the best interests of families, carers and consumers (New South Wales Department of Health, 2013).

The Family and Carer Mental Health Support Program offers targeted support for family members with a mental illness and funds five nongovernment organisations to deliver:
- Education and training packages to teach families and carers about mental illness and its management, and help build coping skills and resilience.
- Individual support and advocacy services for families and carers of people with a mental illness.
- Infrastructure support for peer support groups (New South Wales Department of Health, 2015)

**Nongovernment services**

Nongovernment child and family service organisations, such as ARAFMI and the Schizophrenia Fellowship of NSW, provide services to families to maintain the family unit, and strengthen family capacity to meet the needs of children and families. They provide:

- Education and training to teach families and carers about mental illness and its management, and build coping skills and resilience
- Individual support and advocacy services for families and carers
- Help to establish peer support groups

**Family Support Newcastle**

Family Support Newcastle (previously Newcastle Family Support Services) is a community-managed, nongovernment service that receives funding from state and federal government funding programs, as well as donations from local businesses and groups. It was established in 1979, and is managed by a Board of Management. Its purpose is to assist families with children and young people in their care. The service operates within a philosophy of consumer empowerment through participation in decision making. The agency responds to the needs of families through a range of services, including counselling and individual assistance, therapeutic group programs with associated child development activities; supported playtime activities; community work, and a family centre with a therapeutic and community building focus. A significant proportion of the work involves working with individual families. Within a week of referral, a family worker arranges to meet with the family at a time convenient to both, inviting all members of the family to attend, in the belief all have a valuable contribution.
to make. This might not be possible where the person seeking help wants to leave a situation of family violence, however (Family Support Newcastle, 2014a). According to its Mission Statement FSN:

promotes healthy, resilient children and young people growing in flourishing families in just and strong communities. We contribute by providing services which promote the well-being of children and their families, individuals and communities. We particularly aim to reach those who experience ongoing hardship (Family Support Newcastle, n.d.).

Group programs are provided for parents, including specific programs for fathers, sometimes in partnership with other agencies. Parents contribute to planning by contributing their ideas for discussion topics to improve parenting skills, self-confidence, and managing child behaviour. The family centre is situated in a shopping centre to attract families who would not otherwise attend. It operates three days a week, and is a key place for families and children to develop a sense of community within the service. For some families, attending the centre helps to reduce their isolation from the community, as they learn about participating and belonging in a supportive environment (Family Support Newcastle, 2014a). It offers services to families who have newly arrived in Australia, as well as Aboriginal families. The latter have been supported for many years, primarily through, Koti Bulla Umullan, a program specifically for Indigenous families, which was mainstreamed through its programs (Family Support Newcastle, 2014a) but later closed due to changes in federal funding (Family Support Newcastle, 2014b).

The Annual Report (Family Support Newcastle, 2014a) reported that services were provided to 521 parents in 466 families, with 613 children. The majority of families were receiving a pension or benefit, and many had multiple problems. In a survey on family life completed by 210 respondents, 64% identified social isolation, 50% financial stress, and 40% mental health issues as their major concerns. Most felt their determination (77%), love (77%), and experience of managing difficulties (74%) helped them cope (Family Support Newcastle, 2014a).
Headin’ Up project

The Annual Report (Newcastle Family Support Services Inc., 2009) reported that there had been a significant increase in the number of referrals for family members living with mental illness, upwards of 50% of referrals, and a successful funding application had been made to the Federal Community Based Mental Health Program to establish the Headin’ Up project. It subsequently received government funding through the Family Mental Health Support Service in 2007 (Department of Families, Community Services and Indigenous Affairs, 2007) and 2012 (Department of Social Services, (formerly FACSHIA), 2016). The initial funding received in 2007 led to an increase in services to 65 families in the first two years of the program. Family support included weekly home visits, group programs, and telephone support. Aboriginal family support involved collaboration with the Awabakal Newcastle Aboriginal Co-operative.

Headin’ Up offered integrated support to families with children or young people in their care, where one or more members had a mental illness. Services were provided through group programs, individual family work and counselling, and mentoring for children, so that people living with a mental illness were better able to participate in school, family and community life. The objectives of Headin’ Up, as set out in the funding application, were to: (i) enhance the wellbeing of children in families where a member has a mental illness; (ii) increase the capacity of parents to parent their children while living with a mental illness; (iii) increase the capacity of all family members to adequately participate in family and community life; and (iv) facilitate prompt and appropriate access to mental health services. It aimed to achieve these objectives by establishing a service for families where a member has a mental illness, including strength-based, goal-focused individual family support and counselling and group programs.

At the time this study began, Headin’ Up had nine family workers, including the Team Leader, with two of the staff being Aboriginal workers employed to facilitate participation in the project by Aboriginal families with mental health difficulties. The family workers completed a brief questionnaire which collected demographic information, including qualifications, reported in Chapter 8. Two of the family workers were on time-limited contracts and left the agency at their conclusion, as ongoing funding for their positions had
not been assured. Shortly thereafter, the agency was informed that a further year of funding for Headin’ Up would be provided, highlighting the precariousness of family support programs. Funding was subsequently extended by two, and then four, more months until the end of June 2015, with short term services being provided to families until then (Family Support Newcastle, 2015), further highlighting the funding uncertainties agencies such as FSN face.

**Conclusion**

In keeping with the ecosystems approach informing this study, this and the preceding chapter have examined the broader political, social, and community context in which the research was conducted. This chapter has presented the policy, funding, and service arrangements relating to family support services for children and families in Australia, and New South Wales. The policy and funding initiatives that made Headin’ Up possible were outlined, in the context of nongovernment service provision. This account highlighted the uncertainties surrounding the sustainability of family support programs given the short-termism of contracting arrangements within contemporary neoliberal welfare policy. Chapter 7 outlines the research methodology, and Chapters 8, 9, and 10 present the study’s findings relating to the participants’ lived experiences of mental illness, perspectives on support, and on family relationships and communication.
Chapter 7

Methodology

This chapter describes the methodology. It begins by outlining the purpose of the study and the research questions. It provides a rationale for the research design and highlights the relevance of, and fit between, the research methodology, design, and aims, and the case study approach used. It then provides a detailed description of the research procedures, including justification for the use of qualitative and quantitative methods of data collection and analysis. It discusses the trustworthiness (or validity) of the data, the ethical considerations and the benefits and limitations of the research design. Finally, it outlines strategies for communication of the study’s findings to families, the agency and professionals.

Purpose of the study

Research on the social, emotional and physical impact on families with children living with a family member with a mental illness has variously examined how young carers may be effectively supported (Aldridge & Becker, 2003); the impact of parental mental illness on children (Siegenthaler et al., 2012); and the impact on parenting of the mental illness symptoms and treatment of a parent (Diaz-Caneja & Johnson, 2004; Fudge, Falkov, Kowalenko, & Robinson, 2004). More recent research has been family focused, investigating the efficacy of an intervention that includes parents and children, where a parent has depression (Beardslee, Solantaus, Morgan, Gladstone, & Kowalenko, 2012). There is a paucity of research concerning grandparents and foster carers caring for children of parents with mental illness, and children who have a mental illness.

The purpose of this study was to hear directly from adult and child family members living with a mentally ill relative about their experiences of support, from within the family, and from the community. The study aimed to document their firsthand accounts and
perceptions of the issues impacting on these experiences, such as the barriers to accessing services, and factors which facilitated access. The families were approached through the local family support agency where they were clients of a family mental health program. Key informants – parents and carers – in each family were asked how the family managed help seeking, problem solving and decision making, the dynamics of family relationships, and their experiences of helping agencies. Other family members were given the opportunity to participate if they wanted to and the family workers with the agency’s mental health program also participated.

The literature on mental health promotion, prevention and early intervention emphasises the importance of the protective factors in the environment – a sense of belonging in the family, school and community – as an important buffer against mental illness. Conversely, an absence of such attachments and social isolation are considered major risk factors. These protective factors are said to reduce ‘the exposure to risk or they may be compensatory, reducing the effect of risk factors’ (Commonwealth Department of Health and Aged Care, 2000a, p. 13). The implication is that the surrounding environment provides a supportive structure for families that either prevents or militates against the impact of mental illness. Drawing on this knowledge, this study sought to examine the role such support played for a group of families coping with the impact of mental illness. Table 7.1 shows the potential mental health promoting aspects of the family environment, and of community and cultural factors.

### Table 7.1: Protective factors

<table>
<thead>
<tr>
<th>Family factors</th>
<th>Community and cultural factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Supportive caring parents</td>
<td>• Sense of connectedness</td>
</tr>
<tr>
<td>• Family harmony</td>
<td>• Attachment to and networks within the community</td>
</tr>
<tr>
<td>• Secure and stable family</td>
<td>• Participation in church or other community groups</td>
</tr>
<tr>
<td>• More than two years between siblings</td>
<td>• Strong cultural identity and ethnic pride</td>
</tr>
<tr>
<td>• Responsibility within the family</td>
<td>• Access to support services</td>
</tr>
<tr>
<td>• Supportive relationships with other adult</td>
<td>• Community and cultural norms against violence</td>
</tr>
<tr>
<td>(for a child or adult)</td>
<td></td>
</tr>
<tr>
<td>• Strong family norms and morality</td>
<td></td>
</tr>
</tbody>
</table>

Source: Commonwealth Department of Health and Aged Care (2000a)
Research questions

There were two related aspects to this study: the lived experience of mental illness, and experiences of family support, hence the study asked the following research questions:

1. What were the participants’ lived experiences of mental illness?
2. How did participants perceive the relationships and coping ability in their family?
3. Who did participants go to for support?
4. What facilitators and barriers to support did participants identify?

Research aims

As well as achieving a better understanding of the lived experience of mental illness and the nature of family support received by a group of clients from a particular service, the study also aimed to:

1. Give voice to parents and carers who are living with or caring for a family member with mental illness, concerning their experiences of support they had received and the factors impeding access to needed services.
2. Elicit the perceptions and observations of a group of family workers working with these families in the Headin’ Up program of Family Support Newcastle, a government-funded nongovernment family support agency.
3. Add to the growing body of knowledge and understanding of the lived experience of mental illness and its impact on families.
4. Add insights for evidence-based policy and service provision.

Context of the study

This study would not have been possible without the agreement and cooperation of Family Support Newcastle (FSN), a nongovernment agency receiving government funding to implement a family mental health program (COAG, 2006), named Headin’ Up. The research proposal was presented to the FSN’s management group for discussion and this was followed
by several meetings to clarify roles and objectives. Approval to proceed with the study was obtained in 2008. All participants in the research were clients or employees of FSN.

**Research strategy: Case study approach**

The research strategy chosen was the case study approach using both quantitative and qualitative methods of data collection and analysis. The case study approach was considered a good fit with the research aims since it ‘allows investigators to retain the holistic and meaningful characteristics of real-life events’ (Yin, 2003, p. 2). According to Yin (2003), in contrast to other research methods, the case study offers a method of empirical inquiry to examine a system of action while retaining the meaningful characteristics of real-life events – ‘such as individual life cycles, organisational and managerial processes, [and] neighborhood change’ (p. 2). Given the ecological approach taken, it was important that the research approach used investigated not only the immediate phenomenon under study – family experiences of support – but also the surrounding environmental factors impacting on this phenomenon, such as the policy and service context (discussed in Chapters 5 and 6) in which family support was offered to, and received by, participants (see Figure 7.1).

**Figure 7.1: The case study**

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[Diagram showing Policy context, Agency/service context, Families and family workers]
```
The case study approach not only accommodates the holistic, ecosystems perspective but also allows for use of a mix of quantitative and qualitative methods of data collection and analysis (Yin, 2003). Qualitative methods are suited to research studies where detailed understanding of the area of investigation is best gained by speaking with the people concerned (Creswell, 2013).

The case study approach is not new to social work research. Though its origins are in sociology, ‘the idea of the case study seems to have had a lot do with the social worker’s “case history” or “case work”’ (Platt, 1992, p. 19; see also Richmond, 1917/1964). Key texts concerning the case study tradition published in the 1920s used data from social work case records, and some early textbook writers took it for granted the data available for case study use would come from social work records. Platt (1992) traced the elaboration of the case study method in sociology observing that, until the 1930s, a key feature was the access it provided to ‘data of a special kind’ (p. 20), namely, personal meaning. This feature of the case study method died away over the next three decades due to the increasingly popular quantitative methods in use being unable to deal with the subjective data, or ‘meanings’, generated by the qualitative method of case studies. The period during and following World War II was one of enormous developments in attitude measurement and systematic interviewing due to the availability of substantial resources and large study samples for studies using repeated measures. In this environment, the lack of replicability and generalisability of case studies became deeply problematic. Platt’s (1992) examination of the work of four case study researchers revealed that none of the authors ‘succeeded in describing a non-quantitative model of analysis sufficiently … to provide [precise] instructions which could be followed’ (p. 23) in comparative studies. Platt (1992) found that case studies published during the 1920s to the 1940s were difficult to replicate, findings could not be generalised and it was not possible to make predictions from them. However, case study proponents argued they could predict individual outcomes with some certainty. Social workers, in particular, expressed a practical interest in making predictions, particularly in relation to social problems, such as ‘juvenile delinquency, parole success, and social adjustment in the family’ (Platt, 1992, p. 28). Others argued prediction was impossible ‘without quantitative knowledge of other cases’ (Platt, 1992, p. 31), while Stouffer (1930, in Platt, 1992) demonstrated that a simple attitude
scale could give the same results as a professional judgment based on a case history and thus provided a statistically adequate basis for prediction. Experimental studies led to a ‘mistrust of more impressionistic methods’ (Platt, 1992, p. 34), and the survey method predominated in research.

A revival of interest in qualitative research, which began in the 1950s and 1960s, led to the return of serious discussion on the ‘case study’ method in the late 1980s (Feagin, Orum, & Sjoberg, 1991; Ragin & Becker, 1992; Yin, 1989). Growing enthusiasm for the case study followed even though its advocates did not present a shared methodological position.

**Case study: Definitions and features**

Theodorson and Theodorson (1970) defined a case study as:

> A method of studying social phenomena through the thorough analysis of an individual case. The case may be a person, a group, an episode, a process, a community, a society, or any other unit of social life. All data relevant to the case are gathered, and all available data are organized in terms of the case. The case study method gives a unitary character to the data being studied by interrelating a variety of facts to a single case. It also provides an opportunity for the intensive analysis of many specific details that are often overlooked with other methods (p. 38).

Luck, Jackson, and Usher (2006) distilled definitions of case study from several researchers to define case study as ‘a detailed, intensive study of a particular contextual, and bounded, phenomena that is undertaken in real life situations’ (p. 104). Yin (1981) saw the distinguishing characteristics of the case study as its ‘attempts to examine (a) a contemporary phenomenon in its real-life context, especially when (b) the boundaries between phenomenon and context are not clearly evident’ (p. 59). For Yin, the unique strength of the case study ‘is its ability to deal with a full variety of evidence – documents, artifacts, interviews, [and] observations’ (Yin, 1981, p. 8). For Stake (1995), a case study was:

> … expected to catch the complexity of a single case … We study a case when it itself is of very special interest. We look for the detail of interaction with its context. Case
study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances (p. xi).

According to Gilgun (1994), with its focus on contextual detail, the case study has ‘great potential for building social work knowledge’ (p. 371). Further, the ecosystems framework, ‘with its notions of multiple interacting contextualized systems, helps conceptualize the contexts in which the unit of analysis is embedded … [and] leads to the identification of contextual variables that influence the unit of analysis’ (p. 375).

Yin (2009) considered the opportunity to use different sources of evidence to be a major strength of the case study, with the most important advantage being ‘the development of converging lines of inquiry’, or a process of corroboration (pp. 114–116 emphasis in original). With corroboration, ‘the events or facts of the case study have been supported by more than a single source of evidence’ (Yin, 2009, p. 116). Figure 7.2 illustrates the sources of the converging lines of inquiry in the present study through interviews with families and family workers, and through completion by families of several questionnaires. The family workers’ responses complemented and added perspective to the family interviews.

A further feature of the case study approach already mentioned is its ability to embrace a mix of quantitative and qualitative methods (Yin, 2003). Vallis and Tierney (1999) combined quantitative and qualitative methods in their case study of hip fracture care in hospitals. They concluded that bringing together these methods of data collection and analysis illuminated different aspects of their study and assisted in the ‘interpretation of complex, interrelated aspects of service management and patient care’ (p. 32). While mixing methods does not necessarily ensure validity, it does contribute to ‘completeness’ of understanding of the phenomena under study (Vallis & Tierney, 1999).

**Figure 7.2: Sources of converging lines of evidence**

<table>
<thead>
<tr>
<th></th>
<th>Family members</th>
<th>Family workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td>Experiences and perceptions of families and family workers</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Questionnaires</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

152
A case is defined by its boundary, making it a specific instance, among others (Stake, 1995; Yin, 1981, 2003) – ‘a case of something’ (Punch, 2005, p. 145). Hence the case needs to be clearly identified to preserve its wholeness, unity and integrity, determine the unit of analysis under study, and make the logic and strategy of the research clear. However, not everything about a single case can be studied. Hence the research questions need to define the focus of the study (Punch 2005).

Stake (1995, 2000) and Yin (2003) respectively categorised case studies as intrinsic, instrumental and collective, or explanatory, exploratory and descriptive, set out in Table 7.2. According to Stake’s (1995, 2000) categories, the present research constituted an instrumental case study, where the intention was to conduct a detailed empirical study of a complex, contemporary phenomenon, that is, families’ experiences of support, while, according to Yin (2003), it could also be categorised as exploratory.

Table 7.2: Categorising case studies

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td><em>Intrinsic case study:</em> conducted because there is a 'need to learn about that particular case’ (Stake, 2000, p. 437).</td>
<td><em>Explanatory case study:</em> conducted to explain the ‘how’ and ‘why’ of relationships between events.</td>
</tr>
<tr>
<td><em>Instrumental case study:</em> conducted where the researcher focuses on an issue of concern and selects a bounded case to illustrate the issue and gain insight into the question (Stake, 2000, p. 437).</td>
<td><em>Exploratory case study:</em> conducted to identify outcomes of an intervention.</td>
</tr>
<tr>
<td><em>Collective case study:</em> the study of a number of cases ‘in order to investigate a phenomenon, population, or general condition’ (Stake, 2000, p. 437).</td>
<td><em>Descriptive case study:</em> conducted to analyse and describe a sequence of events over time.</td>
</tr>
</tbody>
</table>

Creswell (2013) has followed the discussions of case studies presented by Stake (1995) and Yin (2009), and summarised their defining features, as shown in Table 7.3. The right-hand column shows how the present study design aligns with these features.
Table 7.3: Comparison of the defining features of a case study with the present study

<table>
<thead>
<tr>
<th>Defining features of a case study</th>
<th>Present study</th>
</tr>
</thead>
<tbody>
<tr>
<td>A ‘bounded’ system</td>
<td>A group of 12 families, clients of a family support agency, set in a policy context of mental health and family support.</td>
</tr>
<tr>
<td>Intent of the case</td>
<td>To understand a specific issue – an instrumental case, aimed at exploring the experiences of a marginalised group relating to their experiences of support.</td>
</tr>
<tr>
<td>Presentation of an in-depth understanding of the case</td>
<td>Collection of information concerning the policy context, the service environment, the experiences of parents, carers and family members, and perceptions and observations of family workers.</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Qualitative analysis of interviews, including presentation and interpretation of identified themes; quantitative analysis of questionnaire responses.</td>
</tr>
<tr>
<td>Description of the case</td>
<td>The family group studied was a ‘bounded system’ in the context of an agency, and policy frameworks. These are described, together with the themes arising from the interviews conducted, and interpretations of themes.</td>
</tr>
</tbody>
</table>

Limitations of case study research

The case study sought to illuminate ‘the research participants’ subjective meanings, actions and social contexts, as understood by them’ (Fossey, Harvey, McDermott, & Davidson, 2002, p. 717). The study was exploratory, and since it sought to illuminate a single case, its findings cannot be generalised to all instances of family support. Critics of case study research point to its limitations in contributing to evidence-based practice due to this lack of generalisability (Liamputtong, 2009; Luck et al., 2006). However, while large studies have breadth in numbers, case study research offers depth (Flyvbjerg, 2006), and enhances knowledge ‘through the study of the particularities and complexities of a bounded system’ (VanWynsberghe & Khan, 2007, p. 6).

A second limitation of case study research is the intensive involvement of researchers with participants, particularly when interviewing people in their homes, as in this study. Participants might feel scrutinised and change their behaviour to present a ‘good face’ to the
researcher, providing ‘acceptable’ responses rather than describing their actual experiences (Liamputtong, 2009).

**Research process and approach**

**Case selected for study**

The ‘case’, or bounded system, in the present study was a group of families who were clients of the Headin’ Up program offered by Family Support Newcastle (FSN). The unit of analysis, or ‘phenomenon for which evidence is collected’ (VanWynsberghe & Khan, 2007, p. 5) was the participants’ first-hand accounts of their experiences of support. The case comprised the families, the agency/service context and the mental health and child and family welfare policies prescribing the family support intervention (as discussed in Chapter 5 and 6). The case study sought to gain an understanding of the nature of supportive connections for families, both within and outside the family, and factors impacting on these, such as the perceptions and experiences of families concerning access to services, or barriers to access. It was informed by knowledge and understanding of the key protective factors for the promotion of mental health that undergirded the extant policies (Commonwealth Department of Health and Aged Care, 2000a, 2000b), namely, a sense of connectedness, attachment to and being part of community networks, and access to support services. Table 7.4 outlines the research process followed. The study began with a review of the literature pertaining to this study, followed by investigation of the policy and agency context, conducting of interviews, and data analysis, with some stages occurring concurrently.
Table 7.4: Stages in implementation of the case study

<table>
<thead>
<tr>
<th>Stage</th>
<th>Activity</th>
<th>Purpose</th>
</tr>
</thead>
</table>
| **Stage 1: Literature review** | A review of the theoretical literature was undertaken relating to:  
. ecological theory  
. theory of stigma  
. theory of recognition  
. social support theories. | Presentation of prior research, the theoretical context of the study, and contemporary knowledge on family support and mental health. |
| **Stage 2: Policy context** | Review of the literature – and policies – on mental health and family support.  
Study of policy context, and agency, Family Support Newcastle. | Overview of the broad policy context, and the agency context of the study. |
| **Stage 3: Data collection** | Families - interviews with family members and completion of questionnaires by primary parent or carer.  
Family workers - focus groups. | Exploration of families’ and family workers’ experiences and perceptions of support available to families. |
| **Stage 4: Data analysis** | Interviews and focus groups - initially coded using NVivo software, with themes then identified.  
Questionnaires - responses analysed with descriptive statistics. | Coding and thematic analysis of responses. |
| **Stage 5: Reporting** | Interpretation and reporting of findings. | Presentation of findings. |
| **Stage 6: Dissemination** | Providing a summary to Family Support Newcastle and to participating families; and to professionals through submission of articles to refereed journals, and conference presentations. | Providing feedback to the agency, and to participating families, and disseminating information to professionals. |

Research paradigms determine ‘the very structure of acceptable explanation’ (Heineman-Pieper, Tyson, & Heineman Pieper, 2002, p. 17). Though a mix of methods was used in this case study, the overarching design was qualitative as it sought to gain an in-depth understanding of families’ experiences of support (Denzin & Lincoln, 2005; Fossey et al., 2002). Qualitative or naturalistic enquiry provided the ‘logically related assumptions,
concepts, or propositions’ that oriented this research (Bogdan & Biklen, 1998, p. 22) (see Table 7.5).

Table 7.5: Interpretive frameworks

<table>
<thead>
<tr>
<th>Paradigm</th>
<th>Ontological beliefs (the nature of reality)</th>
<th>Epistemological beliefs (how reality is known)</th>
<th>Axiological beliefs (role of values)</th>
<th>Methodological beliefs (how to find out)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constructivist</td>
<td>Multiple realities are constructed through our lived experiences and interactions with others.</td>
<td>Reality is co-constructed between the researcher and the researched and shaped by individual experiences.</td>
<td>Individual values are honoured, and negotiated among individuals.</td>
<td>Use of an inductive method of emergent ideas obtained through interviewing, observing, and analysing texts.</td>
</tr>
<tr>
<td>Critical, pragmatic, and transformative</td>
<td>Reality is not neutral but reflects power and identity struggles. Seeks knowledge that is useful, practical, ‘works’, and can lead to change. Questions privilege based on race or ethnicity, class, gender, mental abilities, and sexual preference.</td>
<td>Reality is known through the study of social structures, freedom, and oppression, power, and control. Reality is co-created between researcher and researched. Reality can be changed through research.</td>
<td>Values of the dominant and oppressed need to be problematised and interrogated. Inclusive of researchers’ and participants’ views. Diversity of values is recognised though championing particular groups, means taking a particular political stance or standpoint.</td>
<td>Collaborative processes are encouraged that highlight social issues and concerns. Starts with assumptions of power and identity struggles, documents them, and calls for action and change.</td>
</tr>
</tbody>
</table>

The qualitative research paradigm is a set of regulatory assumptions about what is real (ontology), how to know that reality (epistemology), the role of values (axiology), and the methodology for conducting the research (Cresswell, 2013). It is informed by an interpretivist, constructivist phenomenological view of the world emanating from the philosophy of Husserl and Dilthey respectively (Mertens, 2005, citing Eichelberger, 1989). Interpretivist constructivist researchers rely on rich descriptions only amenable through qualitative data.
collection methods, such as in-depth interviewing and, from this, seek to ‘generate or inductively develop a theory or pattern of meanings’ (Creswell, 2003, p. 9). In so doing, they rely on the participants’ views of the situation being studied while, at the same time recognising the impact of their own positionality on the research design and their interpretation of the findings (Mackenzie & Knipe, 2006). It is a subjectivist form of research as distinct from objectivist quantitative research designs.

Part of the social work perspective that permeates so-called transformative research is a critical theoretical understanding of power and identity and struggles related to oppression arising from class, race, gender, identity, and disability discrimination and exclusion, as well as the social and economic structures giving rise to this (Creswell, 2013). To the extent that this research sought to give voice to clients who are usually silenced in dialogues about service provision, this research is transformative (Mackenzie & Knipe, 2006). Ultimately, it sought to improve services for families living with mental illness, and inform the institutions providing, and policies undergirding, community family support services.

The qualitative and quantitative methods used in the study aimed primarily to gain as close an understanding as possible to the experiences of families coping with mental illness and how they were supported by a particular program.

The justification for the use of qualitative and quantitative methods in a single study was examined by Greene, Caracelli, and Graham (1989), who reviewed 57 mixed-method evaluation studies. Bryman (2006) elaborated on this work and conducted a content analysis of 232 social science articles in which qualitative and quantitative methods had been used, and from these derived 18 reasons that had been given for combining methods. Two of these rationales are applicable to this study: process – ‘quantitative research provides an account of structures in social life but qualitative research provides sense of process’, and completeness – use of both qualitative and quantitative procedures leads to a ‘more comprehensive account of the area of enquiry’ (Bryman, 2006, p. 106). The combining of qualitative and quantitative procedures is designed to give a richer description of family experiences than would be achieved with one method alone.
The qualitative interview method used in the present study was designed to give participants the opportunity to speak freely about their experiences and perceptions of support, the processes of family life. The questionnaire procedure was designed to elicit self-reports to statements concerning family functioning, and coping ability, the structures of family and social life, with findings from one method potentially enhancing the findings of the other. The questionnaires are described below, under the heading *Quantitative measures*.

**Recruitment of participants**

In-depth qualitative research that yields lengthy transcripts usually draws on small sample sizes. Over a period of 12 months 12 families were referred to the research study. Nine family workers participated in focus groups.

**Families**

Families were recruited through the Headin’ Up program, with two key inclusion criteria for the participation of families in the research: first was their voluntary agreement to learn more about the project and participate in the study, and second was that they had a family worker in the Family Support Newcastle (FSN) Headin’ Up program. The involvement of family workers was important and necessary for two reasons, first, they had an important role in telling families about the research, and then referring them to the researcher. This direct referral of families was preferable to alternatives, such as letters mailed via the agency to families, or notices in the agency community centre that some, but not all, families might have attended. The second reason for family worker involvement was the support role they played with families. This was important in the event of a family becoming distressed in any way by participating in the research.

An information sheet was prepared for family workers outlining their role in relation to speaking about the research with families (see Appendix II). A second information sheet briefly outlining the research was also prepared for families and given to them by their family worker who asked whether they could pass the family’s name and telephone number on to me (see Appendix III). When the family worker advised that a family was agreeable to contact
from me I telephoned the parent or carer to explain the research further. At the end of this phone call we made a mutually convenient time to meet. Eleven of the 12 families elected to meet at their home.

**Family workers**

Agreement for the involvement of the team leader and family workers in two focus groups was requested from the management of FSN, who agreed that staff could participate in work time and that FSN premises could be used. The proposal to conduct focus groups with them was discussed with the family workers at a monthly team meeting.

**Data collection measures**

The data was collected using a combination of qualitative and quantitative methods. The qualitative data was collected via in-depth interviews in the participants’ natural settings. The quantitative data was collected via several scales pertaining to family functioning.

**Quantitative measures**

Quantitative data were gathered via completion by adult participants of a series of questionnaires. During the interviews, the parent and carer participants were asked to complete the following questionnaires:

1. Family Background Questionnaire (FBQ), completed at the first interview only
2. MacMaster Family Assessment Device General Functioning subscale (FAD-GF)
3. Family Crisis Oriented Personal Scales (F-COPES)
4. Service Coordination (SC)
5. Family Participation in Planning (FPP)
6. Services your family may have been involved with (see Appendix VI for measures).
Family Background Questionnaire (FBQ)

The Family Background (FBQ) questionnaire, developed by the researcher, was designed to gather demographic information. It included questions about household composition, income level, level of education, country of origin, and marital status. The questionnaire was completed at the first interview only.

MacMaster Family Assessment Device General Functioning subscale (FAD-GF)

The McMaster Family Assessment Device (FAD) was developed to evaluate families according to the McMaster Model of Family Functioning (Epstein, Baldwin, & Bishop, 1983). The FAD is a self-report measure comprising 53 items designed to measure family functioning on seven subscales: problem solving, communication, roles, affective responsiveness, affective involvement, behaviour control, and general functioning (GF). This study used the Family Assessment Device-General Functioning subscale (FAD-GF) comprising 12 items rated on a four-point scale from strongly agree to agree, disagree, or strongly disagree (rated from 1 – 4). The 12 FAD-GF items are a highly intercorrelated subset of those items which correlated highly with all six scale scores derived in the course of development of the FAD (Epstein et al., 1983). Six of the FAD-GF items are worded to reflect healthy family functioning, and six worded to reflect unhealthy functioning, and each item, while belonging exclusively to the GF sub-scale, reflects aspects of the other six dimensions (Epstein et al., 1983). The high correlation of the FAD-GF with the longer FAD and its brevity made it a useful measure of overall family wellbeing (Byles, Byrne, Boyle & Offord, 1988). The FAD-GF was used in the Ontario Child Health Study (Byles et al., 1988), the Western Australian Child Health Survey (Silburn et al., 1996), and a survey of the mental health of children and adolescents in Great Britain (Meltzer, Gatward, Goodman, & Ford, 2000). The FAD-GF has good reliability, internal consistency, and validity (Byles et al., 1988; Fristad, 1989; Miller, Epstein, Bishop, & Keitner, 1985). Scoring of the FAD-GF is undertaken by summing the values of responses, (1-4), and dividing by the number of items (12) to give a total score ranging from 1 to 4. Negatively worded items are reversed. Individual scores range from 1.0, best functioning, to 4.0, worse functioning (Miller, Ryan, Keitner, Bishop, & Epstein, 2000).
Family Crisis Oriented Personal Scales (F-COPES)

The F-COPES is one of the few measures available to measure a family’s coping ability (Fischer & Corcoran, 2007). F-COPES was designed as a 30-item scale, but one item was deleted from the final scale by its authors (McCubbin et al., 1996, i.e., ‘exercising with friends to stay fit and reduce tension’). The F-COPES comprises five subscales with a different number of items in each subscale (in parentheses):

1. 
   Acquiring social support (9): ability to try to get help from relatives, friends, neighbours, and extended family.
2. 
   Reframing (8): ability to redefine crises to make them more manageable.
3. 
   Seeking spiritual support (4): ability to acquire spiritual support.
4. 
   Mobilising family to acquire and accept help (4): ability to seek out community resources and accept help from others.
5. 
   Passive appraisal (4): ability to ignore problems and minimise reaction
   (Fredman & Sherman, 1987).

Each item was scored on a five-point scale: ‘strongly agree’, ‘agree’, ‘neither agree nor disagree’, ‘disagree’, ‘strongly disagree’, with the items in the Passive Appraisal sub-scale being reverse scored. The scale was used by Yatchemoff, et al. (1998) in a study of enrichment and stress in families caring for a child with serious emotional disorder, and by Greeff, Vanstevenwegen, and Ide (2006) in a study of resiliency in families with a member with a psychological disorder.

Service Coordination (SC)

This nine-item questionnaire was adapted and refined by Koren and Paulson (1997) - from a self-report instrument developed by DeChillo and Lebow (1992) - for use in a study of service coordination in children’s mental health from the caregiver’s perspective. The statements were designed to elicit the caregiver’s experience of coordination and cooperation among services involved with the family. The statements were rated on a five-point scale from not true to a little true, somewhat true, mostly true, or very true (from 1-5). Four of the statements were reverse-scored (that is from 5-1).
Family Participation in Planning (FPP)

This six-item questionnaire was developed by Yatchemoff et al. (1998) for use in their study of enrichment and stress in families caring for a child and serious emotional disorder. For the present study, the planning concerned the family, not only the child, and the wording of statements was changed accordingly. Caregiver responses indicated how much they felt they were involved in the practical planning of services, and the degree to which their ideas were valued and the influence they felt they had in plans made for their family. Each statement was rated on a four-point scale from 1-4.

Services your family may have been be involved with

This questionnaire was developed for the present study and comprised a list of 14 services and agencies with which the family may have been involved, such as general practitioners, community health departments, mental health services, and school counsellors. Space was provided at the bottom of the page for inclusion of services not listed. Research participants were asked to tick ‘Yes’ for each of those services they had used, and add others not already listed.

Family workers were asked to complete a Family Worker Background Information form which asked for details relating to age, gender, whether they worked full- or part-time, and level of professional qualification.

Pilot study of the quantitative measures for families

Following HREC (Human Research and Ethics Committee) approval of the research protocol and questionnaires, two families who were current clients of the FSN Headin’ Up project were approached by their family worker and volunteered to pilot test the questionnaires. In response to this process, one change was made to the wording in Statement 2 of the Service Coordination Questionnaire with the word ‘agencies’ substituted for ‘service providers’.

Qualitative measures

Qualitative data was collected through interviews with family members, and family workers to explore their experiences and perceptions relating to support issues for the families. A semi-
structured interview guide was used to ensure the same questions were asked and data collected for all participants, and served as a guide for the interview, rather than dictating the structure and content of the interview (Smith & Osborn, 2004). Preparation of an interview guide forced the researcher to think about the topics to be covered, the questions to be asked and possible sensitive areas of inquiry, and how these might be managed if the participant were to experience distress. The flexible format of a semi-structured interview enabled exploration of areas important to the participant. They were often the ‘most valuable precisely because they [came] … unprompted from the respondent, and [we]re therefore likely to be of especial importance for him or her’ (Smith & Osborn, 2004, p. 233). Interview guides were designed for interviews with:

1. Parents and/or children who had a mental illness themselves.
2. Parents and/or children who lived with a family member who had a mental illness.

These two interview guides were similar and guided the researcher in speaking with adults and children about mental health issues and their experiences of support from family, friends, and the community (see Appendix IV). Participants were also invited to comment on the factors they considered to be barriers to accessing services, and factors that facilitated access to services. As described above the interview guides provided a flexible format so that participants could raise topics important to them which were pertinent to the research, and added richness to the data (Smith & Osborn, 2004).

The topics for the focus groups with the family workers were set out in the Information Statement (Appendix V), with family workers invited to discuss the impact on support issues for families arising from involvement in the Headin’ Up program, and the service gaps and interagency issues which may affect support services to families. A flexible interview format was also followed with the family workers. Table 7.6 shows the procedure for data collection (Sandelowski, 2003).
Table 7.6: Procedure for data collection and analysis

<table>
<thead>
<tr>
<th>DATA COLLECTION</th>
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<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Data source</strong></td>
<td><strong>Interview 1</strong></td>
<td><strong>Interview 2</strong></td>
</tr>
<tr>
<td>FAMILIES: Domain of interest - family’s experiences of support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recorded interviews</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Questionnaires</td>
<td>FBQ</td>
<td>F-COPES</td>
</tr>
<tr>
<td></td>
<td>F-COPES</td>
<td>FAD</td>
</tr>
<tr>
<td></td>
<td>FAD</td>
<td>SC</td>
</tr>
<tr>
<td></td>
<td>SC</td>
<td>PP</td>
</tr>
<tr>
<td></td>
<td>PP</td>
<td>Services involved</td>
</tr>
<tr>
<td>FAMILY WORKERS: Domain of interest – perceptions of family experiences of support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus groups</td>
<td>2</td>
<td>N/A</td>
</tr>
<tr>
<td>Recorded interview</td>
<td>1</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**DATA ANALYSIS**

**Interviews with families**

Individual interviews were conducted with families, rather than focus groups, as families did not know one another, they would have needed to travel to a meeting venue, childcare would have been required, or parents may have wanted to have their children with them, and they would need to be available at the same time and date, in groups of four or five. As the research proceeded, the decision to conduct individual interviews proved to have been the right choice. Some parents/carers wanted to maintain their privacy, and others were ambivalent about their responses being useful to the research. In hindsight, it is likely that the majority of the parents/carers would not have been comfortable in a group meeting.

All family members interviewed agreed to audio-recording of the first and, where relevant, second interview. Data collection with the parent or primary carer in each family was conducted via two interviews at approximately six month intervals, and with several
family members who were interviewed once only. Parents and carers were asked to complete six questionnaires at the first interview, and five at the second interview. The family workers participated in focus groups. The combination of qualitative and quantitative measures provided six sources of data: two sets of questionnaires, two sets of interviews with parents and carers and interviews with several family members, and two focus groups with family workers.

First interview with family participants

Twelve parents or carers agreed to participate, together with the partner of one parent, and two young people in another family. In keeping with the strict ethical requirements for this study, at the first meeting the parent or caregiver was handed the ‘Information Statement’ (see Appendix VI) describing the research, and the rights and responsibilities of participants and researchers. In two cases, the participant asked me to read this, as English was not the first language of these parents. I responded to queries and comments about the research and only proceeded once the ‘Informed Consent’ form (see Appendix VII) had been signed. One parent was being visited by a community worker when I arrived for the first interview. Although the parent preferred to speak in English, the worker spoke briefly with her in her first language to help her understand the interview process.

With the support of their parent two young people agreed to participate. The Information Statement was given to them (see Appendix VIII and Appendix IX) and their rights and responsibilities as participants clearly described. They signed the consent form, with the parent also signing the consent form for the younger participant. The interviews with the young people were conducted in their home.

The partner of one participant was at home at the time of the first interview, and expressed interest in the research. He was invited to participate, and agreed to do so. The Information Statement was mailed to him, and a meeting time arranged, at his home. His rights and responsibilities as a research participant were explained, and the consent form signed. This participant was not available for a second interview.

Following introductions and opportunities for questions, the parents and carers completed the questionnaires. In three cases, the participant experienced some difficulty in
understanding a statement in the questionnaire, so a brief explanation of the intent of the statement was offered. I emphasised to participants that they give the response which best reflected the degree to which the statement applied to their family. Completion of the questionnaires took between 15 and 20 minutes.

The second part of the interview involved audio recording of the discussion. The interviews with the two young people and the partner were also audio recorded. The first interviews varied in length from 20 minutes to an hour and 20 minutes. Following each interview the audio file was sent via internet to a transcription service where it was transcribed verbatim.

Second interview with mothers, grandmothers and foster carer participants

The second interview occurred approximately six months after the first, with one parent interviewed after three months. The interview was conducted to elicit information about experiences not described at the initial interview and possible changes in family circumstances. Five of the six questionnaires were completed at this time (the Family Background Questionnaire was excluded) to capture responses at a second time point, thus providing a more complete picture, within a short timeframe, and mothers and carers again participated in an audio-recorded interview. One family had moved away from the area, so the questionnaires were mailed to the mother, with a return, stamped, addressed envelope to a post office box to facilitate security. The second part of the interview component was conducted with the mother by telephone and was not recorded.

The study set out to involve children and adults living with a family member with mental illness, that is girls and boys, mothers and fathers, and other family members interested in participating. As it happened, the 12 primary caregivers were women, with nine being mothers, two grandmothers, and one foster carer. To be inclusive of these three groups the phrase ‘mothers and carers’ has been used most of the time when presenting the findings. When reference is made to all adult participants the phrase ‘parents and carers’ has been used to include the participant who was the partner of one mother.
For clarity of attribution, family participants’ statements are identified as ‘Frances’ – interview 1, or ‘Frances’ – interview 2, and family worker statements are identified as ‘Melanie’, FW; all names are pseudonyms.

**Focus groups with family workers**

The focus group method was chosen for the family workers, rather than individual interviews, for several reasons: the family workers worked together, and had referred families to this research study, the focus group method can be stimulating for respondents, the discussion may assist recall, and participants can elaborate on the responses of others in the group (Fontana & Frey, 1994). These group dynamics were evident in the two focus groups conducted, with family workers following a discussion thread and elaborating on the topic, or having an idea triggered by the discussion.

The focus groups with family workers were also recorded with their agreement. Two focus groups were arranged with the nine family support workers to enable active participation. An email was sent to all family workers which included a copy of the Information Statement which had been prepared for them (Appendix V). Five of the nine responded to the first invitation to participate, a meeting date was set, and a copy of the research consent form and the Family Worker Background Information form was sent to them in preparation for the meeting. One of the family workers was unable to attend that focus group, but attended the second one two months later. The focus group meetings took just over one hour, and were audio-recorded. Family workers who participated in the focus groups (n=8) were asked to respect the confidentiality of the discussion. One family worker was unable to attend either of the focus groups and was interviewed at a later date. The audio files of the focus groups and the interview were also sent via internet to the transcription service.

A follow up focus group/s was not conducted with family workers as employment contracts ended for two family workers shortly after the first round of focus groups, and other family workers left the Headin’ Up program. During the focus groups, family workers spoke about their experiences and observations in working with any family who was involved with the Headin’ Up program; when doing so they may have been speaking about a family participating in this study, but did not identify by name any family they spoke about. Table
7.7 presents a summary of the number of participants, interviews, and questionnaires completed, and is followed by a description of the procedures used to analyse the data.

### Table 7.7: Number of participants, and interviews and questionnaires completed

<table>
<thead>
<tr>
<th>Group</th>
<th>Participants</th>
<th>Audio-recorded interviews</th>
<th>Questionnaires completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary caregiver in family*</td>
<td>12</td>
<td>24</td>
<td>132</td>
</tr>
<tr>
<td>Other family members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults (Peter) **</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Young people (Scott &amp; Tom)**</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Family workers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group 1</td>
<td>4</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Focus group 2</td>
<td>4</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Individual interview</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td><strong>24</strong></td>
<td><strong>30</strong></td>
<td><strong>141</strong></td>
</tr>
</tbody>
</table>

* Interviewed on two occasions ** Interviewed once only.

### Data analysis

The data for analysis comprised the transcriptions of 28 interviews and two focus groups, and the completed questionnaires. The audio recorded interviews with family members took 14.5 hours in total, and the focus groups two and a half hours in total, with each focus group taking approximately one and a quarter hours. This material gave 407 pages of transcript for qualitative analysis. The plan for analysing the data is shown in Table 7.8.
Table 7.8: Data analysis plan

<table>
<thead>
<tr>
<th>Qualitative data: Transcripts of audio-recorded interviews</th>
<th>Quantitative data: Questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent, carer, and family member responses</td>
<td>NVivo software used for initial coding of transcripts, followed by thematic analysis</td>
</tr>
<tr>
<td>Family worker responses</td>
<td>NVivo software used for initial coding of transcripts followed by thematic analysis</td>
</tr>
</tbody>
</table>

Quantitative data analysis

The questionnaires completed by each parent or carer at Interview 1 and 2 were examined, coded and entered into Excel, and imported into SPSS Version 21. Little’s (1988) MCAR (Missing Completely at Random) test was applied to various scales to test whether values were completely missing at random. If values were missing at random, the imputations were calculated and results compared. Reversals for the negatively worded questions were created if indicated and paired T tests or linear mixed models were used to calculate differences in mean values for all scales and subscales over the two interview times. As this was an exploratory study, the Confidence Interval was set at 90%, where applicable, instead of the conventional 95%. See Chapter 10 for quantitative data analysis.

Qualitative data analysis

The qualitative data comprised the interviews with family members and focus groups with family workers. Analysis of the interview content, identification of themes and the interpretation of meaning followed the inductive and iterative procedures of interpretative phenomenological analysis (IPA) (Smith, 1996; 2004; Smith, Flowers, & Larkin, 2009). The philosophical and theoretical influences in the development of IPA were phenomenology and symbolic interactionism (Smith, 1996). IPA ‘aims to explore in detail participants’ personal lived experience and how participants make sense of that personal experience’ (Smith, 2004, p. 40). IPA also recognises ‘the central role for the analyst [researcher] in making sense of that personal experience and is… strongly connected to the interpretative or hermeneutic
tradition’ (Smith, 2004, p. 40). The IPA analytic process first maps out participants concerns through presentation of themes identified in data analysis, followed by the interpretative component in which the concerns are contextualized within cultural and social environments (Larkin, Watts & Clifton, 2006; Reid, Flowers & Larkin, 2005).

Analysis of the transcripts followed a process of reviewing, coding, and synthesizing to identify emerging themes for presentation. The process of coding is a means of providing new contexts for viewing and analysing data (Tesch, 1990), and is not simply giving categories to data (Strauss, 1987). Coding involves conceptualising the data, raising questions, providing provisional answers about the relationships among and within the data, and ‘discovering’ the data in order to move towards interpretation (Strauss, 1987). Coffey and Atkinson (1996) describe coding as a process of data reduction and data complication, in which data is segmented into simple categories, and then expanded and teased out in order to formulate new questions and levels of interpretation. Tesch (1990) defines the second part of this process as recontextualisation – expanding the data into new forms, with new organising principles based on theoretical frameworks, research questions, and the data itself. There were three steps in the handling of each transcript before I began coding.

1. When each transcript was returned by the transcription service I listened to the recording while reading the text, as an initial validation of the transcript. During some interviews background noise, such as children playing, lawn mowing next door partially obscured the speaker. By replaying the audio as often as required I could in most cases capture the words missed by the transcriber.

2. Following this reading the transcript was de-identified and sent to the participant for checking and for their validation so that deletions or changes could be made before the transcript was entered into NVivo for coding. The de-identified transcript of the second interview was also sent to each participant for checking.

3. All transcripts were entered into the NVivo computer-assisted data analysis package (Bazeley, 2007) as text files, once all participants had the opportunity to comment and make changes.

There were three stages to the coding of the transcripts. Using NVivo the first stage involved the creation of free nodes, or codes, to ‘catch ideas as they happen’ (Bazeley, 2007,
This coding process involved reading the 30 transcripts and creating free codes as I proceeded. The free code form revealed 89 codes, and was useful as a way of capturing the many and varied ideas and experiences of participants, and gave insight into the scope of the issues raised in the interviews.

The second stage of the coding process explored the data using the ecosystem framework as a coding hierarchy, with the microsystem being the family, the exosystem being the service system around the family, and the macrosystem being the policy and institutional system which reflects prevailing attitudes and values. This stage of coding gave an ecological perspective to interview responses. The third stage of exploration of the qualitative data combined pre-existing codes, such as those in the semi-structured interview frameworks, and emergent codes, being those topics participants had raised that were important to them (Creswell, 2013). The initial computer assisted coding of interviews was followed up with repeated, systematic, manual exploration of each transcript to exhaust the insights available in the transcripts (Hewitt-Taylor, 2001). This process of immersion in the data facilitated deeper understandings of participant responses, and the review of codes and interpretations. The patterns of meaning emerging from this process of analysis are reported in thematic form, capturing the experiences and perspectives of participants, Chapters 8 and 9.

**Validity and trustworthiness of findings**

Validity is defined as ‘the state or quality of being sound, just, and well-founded’ (Random House Webster’s Unabridged Dictionary, 1999), and has been the topic of ‘much contemporary dialogue’ (Whittemore, Chase, & Mandle, 2001, p. 522) in relation to qualitative research. Other terms have been suggested, with ‘trustworthiness’ (Lincoln & Guba, 1985; Padgett, 2008) being widely acknowledged as a suitable criterion by which to judge qualitative research. The purpose of applying the criteria of validity and trustworthiness to a study is to persuade the researcher’s audience ‘that the findings of an enquiry are worth paying attention to, worth taking account of. What arguments can be mounted, what criteria invoked, what questions asked’ that would persuade others that the research can be trusted (Lincoln & Guba, 1985, p. 290). In response to ongoing dialogue on the validity of qualitative
research Whittemore et al. (2001) developed a series of techniques for demonstrating validity (Table 7.9), which can be used in combination according to the purpose of a specific study. Whittemore et al. (2001) also synthesised key validity criteria developed by various scholars to provide a series of questions to assess primary and secondary levels of validity (Table 7.10, p. 176). The primary level of validity is the focus of the following discussion.

The present study was designed and implemented with the intent of presenting a thesis which contains evidence of accountability, credibility, authenticity, reflexivity and sensitivity, and integrity. Credibility and authenticity refer to the conscious effort of the researcher to establish confidence in an accurate interpretation of the meaning, and ‘truth’, of the data, and accurate portrayal of the individual voices of participants (Whittemore et al., 2001), and can be established through several means, including triangulation and member checking (Lincoln & Guba, 1985). Triangulation, in this study, involved interviewing families and family workers as a means of accessing different perspectives relating to the same phenomena, and seeking comprehensiveness and complementarity in the data (Huberman & Miles, 1994; Mays & Pope, 2000). The use of qualitative and quantitative data collection methods was also a means of achieving complementarity.

Member checking serves a number of purposes, including giving the participant the opportunity to correct errors of fact in the transcription, and to confirm their statements, and is a process which acknowledges their role and authority concerning their data (Padgett, 2008). In this study, several measures were used. Following transcription of each interview and focus group, a copy of the transcript was sent to each participant, with the advice that I would telephone to ask if there was any material in the transcript which caused concern, or whether any changes were needed. Following the second interview with each adult family participant a letter was sent which contained a summary of their responses to interviews and questionnaires, with the invitation to contact me with any questions. Member checking may also include consultation with participants about the interpretations and findings, although this raises both practical and ethical questions (Padgett, 2008), and is a procedure not followed in this study.
## Table 7.9: Techniques for demonstrating validity

<table>
<thead>
<tr>
<th>Type of technique</th>
<th>Technique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design consideration</td>
<td>Developing a self-conscious research design</td>
</tr>
<tr>
<td></td>
<td>Sampling decisions (e.g. sampling adequacy)</td>
</tr>
<tr>
<td></td>
<td>Employing triangulation</td>
</tr>
<tr>
<td></td>
<td>Giving voice</td>
</tr>
<tr>
<td></td>
<td>Sharing perquisites of privilege</td>
</tr>
<tr>
<td></td>
<td>Expressing issues of oppressed group</td>
</tr>
<tr>
<td>Data generating</td>
<td>Articulating data collection decisions</td>
</tr>
<tr>
<td></td>
<td>Demonstrating prolonged engagement</td>
</tr>
<tr>
<td></td>
<td>Demonstrating persistent observation</td>
</tr>
<tr>
<td></td>
<td>Providing verbatim transcription</td>
</tr>
<tr>
<td></td>
<td>Demonstrating saturation</td>
</tr>
<tr>
<td>Analytic</td>
<td>Articulating data analysis decisions</td>
</tr>
<tr>
<td></td>
<td>Member checking</td>
</tr>
<tr>
<td></td>
<td>Expert checking</td>
</tr>
<tr>
<td></td>
<td>Performing quasi-statistics</td>
</tr>
<tr>
<td></td>
<td>Testing hypotheses in data analysis</td>
</tr>
<tr>
<td></td>
<td>Using computer programs</td>
</tr>
<tr>
<td></td>
<td>Drawing data reduction tables</td>
</tr>
<tr>
<td></td>
<td>Exploring rival explanations</td>
</tr>
<tr>
<td></td>
<td>Performing a literature review</td>
</tr>
<tr>
<td></td>
<td>Analysing negative case analysis</td>
</tr>
<tr>
<td></td>
<td>Memoing</td>
</tr>
<tr>
<td></td>
<td>Reflexive journaling</td>
</tr>
<tr>
<td></td>
<td>Writing an interim report</td>
</tr>
<tr>
<td></td>
<td>Bracketing</td>
</tr>
<tr>
<td>Presentation</td>
<td>Providing an audit trail</td>
</tr>
<tr>
<td></td>
<td>Providing evidence that support interpretations</td>
</tr>
<tr>
<td></td>
<td>Acknowledging the researcher perspective</td>
</tr>
<tr>
<td></td>
<td>Providing thick descriptions</td>
</tr>
</tbody>
</table>


Presentation of findings to colleagues and peers also contributes to credibility (Shelton, 2004). During the course of the study four presentations were made at national and international conferences; and when all interviews and focus groups had been conducted a
presentation of findings emerging from the data analysis was made to Family Support Newcastle managers and family workers.

In conducting a qualitative study the researcher aims to accurately portray the individual voices of participants, however, as Sandelowski (1986) has noted, ‘a major threat to the truth value of a qualitative study lies in the closeness of the investigator-subject relationship … [and this threat] can be offset by deliberately focusing on how the researcher influenced and was influenced by the subject’ (p. 30). My research relationship with family participants was a potential threat to authenticity through meeting them in their own homes, and hearing their individual experiences across two interviews, leading to the possibility of my becoming ‘enmeshed’ with my participants (Sandelowski, 1986). It is ‘the closeness of the investigator-subject relationship (which) enhances and threatens the truth value of a qualitative study’ that is the paradox (Sandelowski, 1986, p. 31). This aspect of authenticity relates to the professional training and experience, and values, and ethical behaviour of the researcher, where respect for participants, that is family members and family workers, can be demonstrated through acting in a way they experience the researcher as authentic and genuine (see Table 7.10).

The activity of prolonged engagement is considered a ‘defining characteristic of qualitative studies’ (Padgett, 2008, p. 186), contributing to study credibility through the process of building trust, thereby gaining information free of distortion or inaccuracies. While time with participants in this study was not prolonged, it did involve two in-depth interviews with parents and carers, scrutiny by all participants of interview and focus group transcripts, and summary letters and follow up phone calls described above.

The demonstration of the credibility of a study is strongly linked to dependability (Lincoln & Guba, 1985). Dependability is the qualitative parallel to the positivist technique of demonstrating reliability, which is the repetition of a study to achieve similar, or the same, results. Qualitative studies such as this one are specific to a small group of participants, at a specific time, in a specific location, within the contextual influences of the policy and service environment operating at the time.
Table 7.10: Assessment of primary and secondary criteria of validity

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary criteria</strong></td>
<td></td>
</tr>
<tr>
<td>Credibility</td>
<td>Do the results of the research reflect the experience of the participants, or the context in a believable way?</td>
</tr>
<tr>
<td>Authenticity</td>
<td>Does a representation of the individual perspective exhibit awareness to the subtle differences in the voices of all participants?</td>
</tr>
<tr>
<td>Criticality</td>
<td>Does the research process demonstrate evidence of critical appraisal?</td>
</tr>
<tr>
<td>Integrity</td>
<td>Does the research reflect recursive and repetitive checks of validity as well as a humble presentation of findings?</td>
</tr>
<tr>
<td><strong>Secondary criteria</strong></td>
<td></td>
</tr>
<tr>
<td>Explicitness</td>
<td>Have methodological decisions, interpretations, and investigator biases been addressed?</td>
</tr>
<tr>
<td>Vividness</td>
<td>Have thick and faithful descriptions been portrayed with artfulness and clarity?</td>
</tr>
<tr>
<td>Creativity</td>
<td>Have imaginative ways of organising, presenting, and analysing data been incorporated?</td>
</tr>
<tr>
<td>Thoroughness</td>
<td>Do the findings convincingly address the questions posed through completeness and saturation?</td>
</tr>
<tr>
<td>Congruence</td>
<td>Are the process and the findings congruent? Do all the themes fit together? Do findings fit into a context outside the study situation?</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>Has the investigation been implemented in ways that are sensitive to the nature of human, cultural and social contexts?</td>
</tr>
</tbody>
</table>


The techniques employed to enable a future researcher to repeat the study included providing a detailed or ‘thick’ description of the research design, data gathering and analysis, and limitations encountered. Interviews and focus groups were recorded and transcribed and all raw data catalogued. The use of NVivo computer software assisted in recording the processes of coding and analysing this data, and the use of a research journal assisted in the recording of ideas and decisions.
The applicability, or transferability of the findings of a qualitative study to other populations will be influenced by the researcher providing the ‘widest possible range of information’ relating to all aspects of the study (Lincoln & Guba, 1985, p. 316). With this contextual and procedural detail the reader of the report can form an understanding of the phenomena under study, enabling comparison with the phenomena they observe in their situation (Shenton, 2004). The detailed descriptions of the policy, service, and agency contexts, the recruitment of participants and data gathering and analysis, provides information about the boundaries and limits of the study, and enables practitioners and researchers to reflect on the applicability of this study to their own contexts.

The integrity, or confirmability, of the findings of a study ‘is the qualitative investigator’s comparable concern to objectivity’ (Shelton, 2004, p. 72), or neutrality, although in interpretive research it is the subjectivity of the investigator that is valued, while also existing as a threat to the ‘truth’ of the study (Sandelowski, 1986). I employed techniques such as setting out detailed descriptions of methods, processes, and decisions, which together have provided an audit trail, augmented by consultation with and feedback from research supervisors, and member checking. The verbatim transcriptions of the interviews and focus groups were scrutinised for accuracy by examining them closely against the voice recording, to ensure there were no distortions or errors in the transcriptions.

**Ethical issues and how they were managed**

While my organisational accountability was to The University of Newcastle, I was equally accountable to FSN for the conduct of the research as the agency had permitted involvement of family workers as direct participants, and as referrers of families who chose to participate. I was therefore accountable to the agency for the way in which the research was conducted, and for regular reporting of progress. Further, as a Member of the Australian Association of Social Workers (AASW) I subscribe to the Code of Ethics of that organisation, which includes ethical practice relating to research (AASW, 2010). The University of Newcastle has stringent ethical procedures with which researchers have to conform, including the requirement that researchers have formal approval to proceed from the Human Research Ethics Committee.
Approval for this study was granted on 12 February 2009 (Approval Number H-2008-0430). Hence in preparing for this study, ethical issues had to be anticipated, whether or not the situations eventuated in the study. There were methodological and ethical issues relating to the inclusion of families who were vulnerable due to illness or stigmatisation or both. The methodological issues concerned definition of family, recruitment and retention of participants, and safety concerns. The ethical issues concerned participant’s capacity to give their informed consent to participate, confidentiality, reporting abuse and neglect, conflict of research ethics and personal ethics, identifying problems nobody could fix, balancing demands and benefits, interpretation of data, and interviewing families in their own homes. A meeting was arranged with the Headin’ Up team leader and family workers during preparation of the ethics submission to seek their ideas relating to the processes of the potential involvement in the study of children, young people, people with mental illness, and Aboriginal people. The management procedure for potential concerns or complaints about the research was set out in the Information Statement given to all participants. It gave contact details for the project supervisors and the Human Research Ethics Officer at the University of Newcastle.

**Definition of ‘family’**

From the beginning of this study, ‘family’ included grandparents raising their grandchildren, and foster carers providing long-term care for a child or children. The 2012 report on Australia’s children by the Australian Institute of Health and Welfare (AIHW, 2012b) stated 46.5% of children aged 0-14 years living in out-of-home care were in foster care; a further estimated 19,800 children between 0-14 years were being raised by their grandparents (AIHW, 2012b), including situations where a parent had a mental illness (Cowling, Seeman, & Göpfert, 2015). In the present study, children were being raised by grandparents in two families, and by a foster parent in one family. Demi and Warren (1995) provided examples illustrating the need for flexibility when defining ‘family’, while being clear about who would be the respondent to the research. In the present study, the key respondent was the main, or primary, carer in the household.
Recruitment and retention of participants

Steinke (2004) and Demi and Warren (1995) believed motivation to participate in research by some families might be influenced by deference to perceived authority figures, a need to talk to someone, and feeling they should not refuse. In some instances, families might agree to participate, and later withdraw, or be unavailable for follow up. In the present study, families were first informed of the research by their family worker, who handed them a one-page information sheet about the project and obtained their permission to give the family contact details to me. I then telephoned the family, explained the research further, and arranged the first meeting.

To clarify my relationship with the agency, and with the families: I had no prior contact with the agency before approaching them about my proposal for the research project, and had no knowledge or contact with any of the families until they were referred to me by their family worker.

The agency family worker who had referred each family had no further role, and was not called upon to speak with families concerning the research interviews. Families were informed as part of the initial ‘briefing’ about the research, and again at the conclusion of the first meeting, that they would be contacted about the second interview within six months. At the time this second approach occurred 10 families were immediately agreeable to arranging a meeting. One carer postponed the arranged second meeting due to family issues, but did not state she did not wish to continue. I followed up on two occasions over a period of three months, and then arranged with her to put the interview ‘on hold’ for a while. The second interview was concluded 11 months after the first.

In the case of another family, the composition of the household had changed, so the second meeting was postponed for several weeks, until the carer could feel comfortable about my visiting her home again. This carer demonstrated her commitment to completing her participation in the research by twice telephoning me herself with the information that the timing was right for us to meet. This carer was more comfortable meeting in her own home, rather than another setting.
Financial compensation for participants

Payment of compensation to research participants may be used to provide incentive to participate, and if excessive in amount could be seen as coercion to participate (Nelson & Merz, 2002; Steinke, 2004). The amount of $10 offered for each interview was in acknowledgement of participation, and may have covered all or some of the costs of transport, depending on how the family travelled to the meeting (by car or public transport), and how many family members attended an office based meeting (such as bus fare for parent and two children). However, all families preferred to be interviewed in their own home, with the exception of one parent who lived some distance away, but attended FSN office regularly, and was interviewed there.

Financial compensation of research participants is acknowledged as a possible manipulating factor (Nelson & Merz, 2002; Steinke, 2004) but is commonplace in biomedical research. According to Latterman and Merz (2001), a survey of articles found a cash incentive was used in 83 of 109 studies, with the average hourly payment being USD10, with payments ranging from USD1 to USD730. Nevertheless, the ethical implications of such incentives need to be carefully considered (Steinke, 2004). In the present study, the Information Statement explained that AUD10 would be offered at each of the two interviews to acknowledge the cost of possible travel to the interview. As all families, with one exception, were interviewed in their home, at the time the money was offered it was explained to the parent or carer ‘this money is offered in acknowledgement of your participation’. At the beginning of both interviews an envelope containing the AUD10 was given to the parent/carer, and family member, with the two young people each receiving AUD5. The money was declined on both interview occasions by two families.

Role of ‘gatekeepers’ and other obstacles to referrals to the research

The gatekeeper role might have influenced participation by families, or individuals, in this research. In their report of a qualitative study conducted with 91 members of 29 families caring for children or young people with life-limiting conditions, Stevens, Lord, Proctor, Nagy, and O’Riordan (2010) described unexpected methodological issues, including the
negotiation of access to participants via ‘gatekeepers’. Team leaders had supported the research by writing to the ethics committee, but their support was not always matched by other members of the team who were concerned about impact of the research on families, and evaluation of their own performance. Steps were taken to address concerns, and provide reassurance, but ongoing ‘gatekeeping’ occurred, which affected the time taken for recruitment, and also left the research team without information about how many families had been excluded, or had declined to participate, or the characteristics of these families (Stevens et al., 2010).

In the present study the Management staff of Family Support Newcastle formally approved the development of the project with a letter of support provided to HREC; the team leader provided support through reminders to the family workers to refer families to the project, and by agreeing to the researcher attending team meetings to provide updates. Almost six months elapsed between the pilot interviews and first research interview, with only one more interview being conducted in the following four months. The research momentum then increased with seven families participating in first interviews in the next five months. There followed a gap of four to five months due to lack of government advice to the agency about continuity of funding for the Headin’ Up program. This led to the agency deciding not to accept referrals with, consequently, no families available to be referred to this research during that time. The agency was then advised funding would continue for a further 12 months and three more families participated over the next three months, making 12 families participating in this study.

**Confidentiality and anonymity**

Confidentiality and protection of privacy is particularly important for participants considered vulnerable due to inequality, stigma, or marginalisation (Liamputtong, 2009). All participants had been assured that their participation, and interview material, would be treated as confidential, and that steps to ensure anonymity would be used. This was managed by the use of code numbers and pseudonyms for families. I gave each family questionnaire an identifying number before meeting with or mailing to each participant, that is, each participant was allocated an ID number from 01 to 12 with the ‘Interview 1’ questionnaires labelled ‘A’ and
‘Interview 2’ questionnaires labeled ‘B’, that is, participant one was 01A and 01B. Names were not shown on the questionnaires and the identifying number for each participant was recorded against her or his name and address in a book kept in a secure filing cabinet (the address was needed to post each interview transcript to the participant). Similarly, interview transcripts were given an identification number. The completed questionnaires and transcripts were filed in one locked cabinet, and the signed consent forms for all participants were filed in a second locked cabinet. The family worker background information forms were also given an identifying number, and these and the signed research consent forms were also kept separately in a secure filing cabinet. Four people only had access to this research material, the supervisors and myself. On completion of the research the consent forms and hard copies of data will be securely stored in a locked filing cabinet, where they will be retained for five years from thesis publication. After this time hard copy material will be disposed of through a secure documents removal service, and electronic records will be deleted.

Capacity of research participants to provide informed consent

This study was designed to learn from families living with a family member with mental illness about their experiences of support. It was therefore possible participants might include children, young people, adults, and Aboriginal people, with the further possibility the participants might have a mental illness, and be a member of one, two, or all three of these categories. The submission to HREC had to account for reasons why each of these groups should be participants in this study, and how their capacity to consent to participate, and to actually participate, would be assessed. The way in which these concerns were addressed in this study is discussed below.

Research involving special groups

Research involving children and young people

Involving children and young people in research raised several ethical and methodological issues, including the following:
1. Complete confidentiality could not be guaranteed (Mahon, Glendinning, Clarke, & Craig, 1996).
2. Children should not be taken for granted.
3. Children are not a homogenous group so researchers need to consider age, gender, ethnicity, and developmental level alongside age.

Where children or people with a mental illness were going to be asked to consent to participate in a research study, the HREC asked researchers to explain how the child or young person’s vulnerability and capacity to consent would be judged, or assessed, and how the consent process would take into account the nature of any mental impairment due to mental illness. In relation to children and young people, it was argued that their participation in the research was not contrary to the best interests of the children and accorded with the United Nations Convention on the Rights of the Child (United Nations, 1991b). Children could choose whether or not they wished to participate, but could not do so if their parents did not agree. Young people over the age of 14 years could make their own decision about participation. Hence the participation of children in this study depended on parental permission, as well as their own willingness or otherwise to participate.

Two young people from the same family agreed to participate, with the support of their parent. Separate Information Statements and Consent Forms had been prepared for young people and, before the interview began, the research was outlined verbally, including the audio recording of the interview, and they signed the Consent Form. In the case of the younger child, the parent also signed the form. The young people were interviewed in their own home which provided a familiar environment.

**Research involving Aboriginal people**

The client population at FSN, from which participants in this study were recruited, comprised 10% Aboriginal families. During preparation of the HREC proposal, consultation was arranged with all FSN staff, including the Aboriginal mental health family workers, who advised on the need to respect cultural and social values in development and implementation of the research. The values and ethics framework in which research involving Aboriginal and Torres Strait Islander peoples should be conducted was set out in the National Health and
Medical Research Council (NHMRC) document ‘Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research’ (National Health and Medical Research Council, 2003). These central values and ethics were spirit and integrity; reciprocity; respect; equality; survival and protection; and responsibility. The FSN employed two staff of Aboriginal background to work in the Headin’ Up mental health program, and I consulted these staff members in preparing the submission to HREC, and before meeting with families who identified as Aboriginal and wanted to participate in the study.

**Research involving people with mental illness**

In relation to participants with a mental impairment, the research proposal submitted to HREC argued that as families were the focus of the study it would be assumed adults or parents with a mental illness who were caring for children were sufficiently well to provide care, and participate actively in giving their informed consent, as well as giving informed consent for their children to participate if they wished to do so.

An Australian study analysed 46 previous studies examining distress following participation in research involving the assessment of psychiatric states or associated risk factors (Jorm, Kelly, & Morgan, 2007). Analysis of the earlier studies found that overall, positive effects of participation in research were independent of negative effects. Participants might have become distressed, but also evaluated the research they were involved in positively. In the same study, Jorm et al. (2007) reported a psychiatric study of children which found 19% experienced concern about the research interview, with 59% of those stating the interview had been helpful.

A study of bereaved parents also reported by Jorm et al. (2007) found 78% of those who were distressed also found it helpful, while only 5% found it unhelpful. An explanation offered by Jorm et al. (2007) for participation in research being both distressing and beneficial was that avoiding thoughts and feelings surrounding a traumatic experience was itself a stressor, and while participating in research could be distressing at the time, writing and talking about these experiences could improve health. Jorm et al. (2007) concluded that a minority of participants in psychiatric research became distressed but there was no evidence of longer-term harm.
Parents who have a mental illness and have dependent children have participated in numerous quantitative, qualitative and mixed methods studies in the past 20 years, while in inpatient, community mental health, and community settings, thus providing precedents for their participation.

**Vulnerability and psychological risk**

It was possible that reflecting on family experiences of mental illness, and support, or lack of it, for a family might cause distress during, or following an interview. The Information Statement given to families suggested that the family and I together would arrange to contact a support person of their choice. This could be their family worker or another person.

My experience and professional role as an accredited mental health social worker had some bearing on this issue. For most of the duration of this research project I was employed in a full-time position as a case manager in a child and adolescent mental health service, with prior experience in working with families, and in conducting research with parents with mental illness with dependent children in their care (Cowling, Luk, Mileshkin, & Birleson, 2004), and working collaboratively in community-based projects with consumers and carers in mental health services (Cowling, Edan, Cuff, Armitage, & Herszberg, 2006). Based on this experience, I approached families participating in the present study as partners in the interview process, seeing them as having information important to convey, or ‘yield’, to the project, in contrast to being ‘objectified’ as participants from whom information is to be ‘extracted’. Mitchell and Radford (1996) state ‘research participants are more than data sources and researchers are more than data-collecting instruments; both researcher and participant are subjects engaged in a human relationship’ (p. 52). In their view researchers have a responsibility to listen to disclosures as they arise, and educate respondents when the opportunity occurs, rather than ignore or redirect sensitive topics raised by the participant. In the present study, information was given to participants on some occasions in the course of the interview, such as websites, or the name of an agency. During some interviews, parents or carers described distressing events and gave details of family history, which I acknowledged and responded to.
In relation to the need to manage psychological distress experienced by any participant during an interview, on the three occasions this occurred I expressed my concern with the participant taking the time she needed to feel comfortable with proceeding. One participant was asked if she would like to finish the interview, but she made the decision to continue.

As I progressed through my first meeting with each family I noted the varying levels of confidence and belief each person had in relation to feeling they would usefully respond to the research, although they had agreed voluntarily to do so. This observation alerted me to the need to balance encouragement for the participant and what I believed they could contribute, having respect for their hesitation, and not deliberately causing their discomfort by ‘pressuring’ them to say more.

**Interviewing families in their own homes**

The parents had been referred to the research by their respective family worker who had made an assessment about the family’s potential interest in participating. The families had the option of meeting with me at one of the FSN community centres, but for their own convenience and comfort most chose to meet in their own homes, with one parent meeting with me at the agency office. As Demi and Warren (1995) noted, the informal atmosphere of an interview in the home encouraged friendliness, trust, and self-disclosure. This might be enhanced when the interview, as in the present study, was intended to elicit experiences and perceptions of research participants in their own words. For both professional and ethical reasons, I needed to maintain a balance between ‘allowing participants freedom of expression and pursuing domains of interest on which the study was based’ (Stevens et al., 2010, p. 502), while remaining connected with the family and, at times, listening to distressing emotional issues.

Conducting research interviews in a home setting means other family members may also be present (MacDonald & Greggans, 2008), and this did occur, with both other adults, and children, being present in some cases. In four cases the parent or caregiver was at home alone. In two families another adult family member was home but did not appear. In five families one or more children were also at home. When children were at home they were either absent from the living area in which the interview was conducted, such as playing on a computer elsewhere, moving to and fro between their parent and the computer, or actively
playing in the living area where the interview was conducted. Where children were physically active or required their parent’s attention, I maintained a respectful stance to the parent’s responsibilities, and resumed the interview when the situation had been settled. The presence of children when interviews were being conducted in the home was to be expected in this study, and, further, conducting of research interviews in a family’s home required the capacity to respect that privilege, and also be flexible when the parent needed to attend to the children. In spite of choices made by participants, research interviews in families’ homes involved entering their private environment, a potentially disruptive intrusion into their worlds, and in this case their homes, which I as the researcher could leave.

**Disclosure of child abuse or neglect**

Agreement with FSN concerning my response in the event a child, or parent, disclosed an incident of abuse was established during the preparation of the application to the HREC. I had a mandatory responsibility to report incidents of neglect and abuse to the NSW Department of Community Services. In the context of this research, it would have been preferable if any required action was taken in collaboration with the family worker involved, and the agency. The Information Statements for both parents and children informed them of my mandatory responsibility to notify the NSW Department of Community Services of suspected child abuse or neglect where this became evident during a research interview. No notification was required.

**Safety concerns**

Historically, the focus of human research ethics committees has been the protection of the participants from physical or psychological harm (Dickson-Swift, James, Kippen, & Liamputtong, 2008) but there were, potentially, similar risks for researchers, particularly when engaged in research of a sensitive nature or where families had complex health and psychosocial issues (Demi & Warren, 1995; Dickson-Swift et al., 2008). Before the interviews were conducted it was anticipated at least some of them would be conducted in the homes of participants, and I was therefore required to submit the form ‘Safety Implications of Research Projects Involving Off-site Activity’ to the Health and Safety Department, Human Resource
Services at the University of Newcastle, and to complete a half-day training program on ‘Workplace Violence: Safety Awareness and Aggression Minimisation’. The present study involved interviewing families considered vulnerable in the intimacy of their own homes. In six cases, only the parent or carer was present, in three cases children were at home. In all families, at least one family member had a mental illness, which might have been the respondent or another family member, or both. At no time was I concerned for my safety.

**Communication about the research**

Communicating the research processes, and findings, to the families, the agency, and professionals was an important aspect of conducting the study, and occurred as the study progressed.

**Communication of findings to families**

Following the second interview, the responses to the questionnaires and recorded interview for each family were summarised in the form of a letter and posted to them, including acknowledgement and thanks for their participation. This procedure was included in my application to the Ethics Committee and described in the Information Statement prepared for families. The information was provided only to the parent/carer participants, although they could discuss it with others if they wished. Two weeks after the letter was posted, I contacted each parent/carer to enquire if they had any questions or concerns about the contents of the summary. No queries or concerns were raised.

**Communication to Family Support Newcastle (FSN)**

From the beginning of the research process I sent a brief report every six months to FSN management to account for progress, such as Ethics approval, the number of interviews conducted and, when relevant, conference presentations made. I met with the Headin’ Up family workers at least once each year to give them a research progress report and also asked them to refer families to the research. Throughout the research process I maintained regular
telephone, email, and face to face contact with the Headin’ Up Team Leader in order to receive, and to give feedback about the project.

**Communication to professionals**

In 2009 a journal article was published (Cowling & Lamont, 2009), and in 2009 and 2010 papers were presented at two Australian conferences. These three communications with other professionals outlined the research project in the context of the working partnership between me as researcher and the agency. Each one was co-authored or co-presented with the Headin’ Up team leader. I presented an overview of the research at an international mental health conference in Vancouver, Canada, in 2012; and at a national conference in Melbourne in 2015.

**Potential benefits of the study to participants and others**

Families with complex needs, living with a family member with mental illness were invited through their family worker to participate in this study, to contribute their experiences and ideas concerning accessibility to, or barriers to receiving services. They may have benefited from this participation in one or more of the following ways:

1. **Having the knowledge that a research study was being conducted concerning their experiences was affirming for some.**

2. **After initial hesitation and lack of confidence about being able to contribute, finding they could do so, and that their involvement was appreciated and valued.**

3. **Having someone who listened to their accounts of their experiences, and who, in some cases, gave them information.**

4. **Receiving transcripts of their interviews, and a summary of their responses following the second interview.**

Potential benefits of the study to family workers included participating in the focus groups, and during this discussion reflecting on their work with families, including the positive role they had been able to have in helping a family achieve change, and also reflecting
on their experiences with other agencies. The family workers also received copies of the focus group transcripts, which enabled further private reflection.

A potential benefit to the community was demonstration of the role a nongovernment family support agency may have in promoting mental health and wellbeing of families and children living with a family member with mental illness through demonstrating that services other than mental health can make a contribution in this area, and through demonstration of the collaborative partnership between agency and researcher that occurred (Cowling & Lamont, 2009).

**Limitations of the study**

Limitations of the study related to recruitment of participants, and an interruption in funding to the program, and the intensive involvement this approach required. Recruitment of families to the study was dependent on the professional judgment of family workers about whether or not to discuss the research with the family, based on the complexity of issues affecting the family at the time, which excluded some families. Where the research was discussed with a family by the family worker, an unknown number of these families decided they did not want to be involved, with 12 families deciding to participate.

The study design and protocols provided for inclusion of children and young people, Aboriginal people and those from culturally and linguistically diverse (CALD) backgrounds. Two young people participated, one person identified as an Aboriginal person, and two people were born in countries other than Australia.

Previous research shows that children have a valuable role in adding to knowledge and understanding of their experience of services and supports when their parent has a mental illness (Aldridge & Becker, 2003). Participation of more than two children/young people in this study was limited by the reluctance of all but one parent or carer to involve them in the research. Twelve of the 22 children in the 12 families were aged eight years or older, and their mothers and carers were asked whether or not they would be agreeable to their child or children participating, and whether or not the young people themselves would be agreeable. One mother agreed, on condition her children were comfortable with being interviewed.
Three of the 12 mothers and carers had a partner, and the partner of one mother stated that he wanted to participate. Family members living with a partner, or other family member, with mental illness may feel isolated, helpless, and lack information (Mental Health Council of Australia, 2009), and their experiences of services and support would add to greater understanding of the impact on them, and on the whole family when a parent or family member has a mental illness (Armitage, in Cowling et al., 2006). No fathers or male carers participated as primary carers.

The recruitment of families to the study stopped for a period of six months following an interruption to funding of the program. This resulted in two family workers leaving, and referrals not being accepted to the program by the agency. The interruption in funding also meant that follow up focus groups were not conducted with the family workers due to the changes in staff.

The intensive involvement, in their homes, with the family member participants in the study is another limitation. It is not known the degree of obligation participants may have experienced when agreeing to be involved, or whether they changed their behaviour to provide what they considered to be socially desirable responses, rather than describing their actual experiences.

The small number of primary caregivers who participated in the study (n=12) influenced the statistical power of the analysis of the questionnaire data. Simply, the larger the sample size the greater the statistical power, as the variability of the sampling distribution is decreased, thereby decreasing the overlap between the distribution under the null and alternative hypotheses, which increases confidence in a finding which leads to rejection of the null hypothesis (Shavelson, 1988). The level of significance of results may or may not have been affected by an increase in the number of participants.

In keeping with the exploratory nature of the study, the aim was to learn from participant family members about their experiences and perceptions of support, while also enquiring through parent and carer self-report questionnaires about family communication, help-seeking and problem solving. The purpose in bringing together qualitative and quantitative methods was to gather data from one approach not available to the other, which
would provide a richer description of family experiences than would have occurred with the use of one method only, by illuminating different aspects impacting on the study population: the processes involved in family relationships (the interviews), and the structures relating to social life (the questionnaires). The interviews yielded valuable and extensive insights into parent, carer, family member and family worker perceptions of support experiences and issues. The statistical analysis of the questionnaires resulted in no statistically significant differences from Interview 1 to 2.

**Conclusion**

This chapter has outlined the research questions addressed in this study, the case study research strategy, the qualitative and quantitative approaches for data collection, the processes for participation by family members and family workers, and the measures used for data collection and analysis. Important ethical and methodological issues of concern in this study were also set out, including the capacity of people with mental illness, and children and young people, to give their consent to participate, protocols to manage psychological distress experienced by participants, disclosure of child abuse, and the stance taken by the researcher when interviewing families in their homes. Chapters 8 and 9 present the findings from the interviews with family members and family workers, describing their experiences and perceptions of support for families, followed by presentation of the quantitative findings in Chapter 10.
Chapter 8

Findings: Living with mental illness

This chapter presents the findings of the study on the participants’ experiences of family support for family members living with mental illness. In keeping with the study questions, it presents the findings in relation to the participants’ lived experience of mental illness. However, before presenting these findings, the demographic and household information is outlined as the starting point from which to understand the nature, quality, and usefulness of the support received. To introduce the mothers, grandmothers, and foster carer and their families a brief description is presented in Table 8.1.

Participants’ demographic and household information

During the time the interviews were conducted, 71 families were receiving services from the Headin’ Up program; of these, 12 agreed to participate in the study. These 12 primary caregivers, mothers, grandmothers and a foster carer, completed the Family Background Questionnaire (FBQ), as discussed in Chapter 7 (see Appendix VI). The demographic and household information collected included family income, level of education, country of origin, marital status, household composition, and number of adults and children in the family affected by mental illness (see Table 8.2). The 12 participants were all female primary caregivers, caring for between one and four children; nine (75%) were sole parents, which is significantly higher than the Australian average of 22% (Australian Bureau of Statistics, (ABS) 2007). One was married, two were separated, two were divorced, three were in de facto relationships, and four were single.
**Table 8.1: Brief description of families participating in the study**

<table>
<thead>
<tr>
<th>Family</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alex</strong></td>
<td>is a grandmother parenting her teenage granddaughter who has a parent with mental health issues. Alex became involved as primary carer when her granddaughter was an infant, as she felt there was no other option. While there have been difficult times over the years, Alex’s granddaughter is achieving well at school and other activities, and has plans for her future.</td>
</tr>
<tr>
<td><strong>Beth</strong></td>
<td>is a grandmother parenting her three grandchildren aged 13, 7 and 4 with her husband. She also has a caring role for the parent of the children, who has mental health issues. Beth and her husband have been caring for the two youngest children since they were babies.</td>
</tr>
<tr>
<td><strong>Claire</strong></td>
<td>is a foster carer who cares for an eight-year old child with mental health issues. She also has young adult children of her own. The child's needs make some aspects of life difficult, such as going to activities in the evenings, as there is no-one available to care for him to help Claire.</td>
</tr>
<tr>
<td><strong>Elizabeth</strong></td>
<td>is a single parent with four young children. Elizabeth has a mental illness, and two of her children have developmental disorders, and significant needs related to these. Elizabeth has little contact with her family, and depends on community based services to support her in caring for the children.</td>
</tr>
<tr>
<td><strong>Diane</strong></td>
<td>is a single parent who is affected by mental health issues and lives with her young child. It is difficult to balance the need for her son to have a relationship with his father, alongside the difficulties in the relationship between Diane and the child’s father.</td>
</tr>
<tr>
<td><strong>Rebecca</strong></td>
<td>lives with her husband and two children. Rebecca has mental health issues, as does one of her children. Rebecca’s illness has had a significant impact on her life, but she can manage the fluctuations of her illness, and assertively seeks help and support from health and welfare services.</td>
</tr>
<tr>
<td><strong>Jane</strong></td>
<td>is a single parent with mental health issues. She lives with her five-year old child who has just started school. Jane lived in another state for several years and it has been difficult to form new associations and friendships, although her son attending school has helped this process.</td>
</tr>
<tr>
<td><strong>Tessa</strong></td>
<td>is a parent whose first language is not English, which has been very frustrating for her sometimes, especially when dealing with bureaucracies, and seeking help on the telephone. She has mental health issues as does her 12-year old child, and sometimes she is very stressed by his behaviour.</td>
</tr>
<tr>
<td><strong>Frances</strong></td>
<td>is a single mother of four children aged 16, 15, 8, and one year. Following years of misdiagnosis, Frances has received effective counselling and treatment for mental health issues. This has helped her confidence as a parent, and her relationship with her children.</td>
</tr>
<tr>
<td><strong>Carter</strong></td>
<td>was born in a south-east Asian country, and has a 13-year-old child with an Australian father. Carter is affected by mental health and other issues, and has difficulty with the English language. Carter has no family in Australia and feels very isolated.</td>
</tr>
<tr>
<td><strong>Liana</strong></td>
<td>lives with her partner and two young children, aged seven, and one year. She is affected by mental health issues which have resulted in her being admitted to hospital for treatment several times since she was 18. Grandparents of both Liana and her partner are sometimes available to support the family.</td>
</tr>
<tr>
<td><strong>Helena</strong></td>
<td>is a single parent with two children, aged 15 and 11 years. Helena is affected by mental health issues, and assertively looked for, and is receiving treatment. Helena is aware of her older child taking on ‘parenting’ responsibilities while Helena was particularly unwell.</td>
</tr>
</tbody>
</table>

*Note: Each family contributed to the choice of pseudonym, and summary about their family.*
Table 8.2: Participant demographic and household information (n=13)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Income p.a.</th>
<th>Highest education level</th>
<th>Country of origin</th>
<th>Marital status</th>
<th>Household composition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alex#</td>
<td>&lt;$30,000</td>
<td>Post-secondary</td>
<td>Australia</td>
<td>Divorced</td>
<td>Grandmother, grandchild aged 14</td>
</tr>
<tr>
<td>2. Beth</td>
<td>&lt;$30,000</td>
<td>Year 7</td>
<td>Australia</td>
<td>Married</td>
<td>Grandparents and three grandchildren, 13, 7, &amp; 4</td>
</tr>
<tr>
<td>3. Claire#</td>
<td>&lt;$30,000</td>
<td>Year 10</td>
<td>Australia</td>
<td>Separated</td>
<td>Mother, one other adult family member, foster child aged 8</td>
</tr>
<tr>
<td>4. Elizabeth</td>
<td>&lt;$30,000</td>
<td>Post-secondary</td>
<td>Australia</td>
<td>Single</td>
<td>Mother and four children, 6, 3, &amp; twins aged 1</td>
</tr>
<tr>
<td>5. Diane</td>
<td>&lt;$30,000</td>
<td>Year 7</td>
<td>Australia</td>
<td>Single</td>
<td>Mother, one child aged 3, Indigenous family</td>
</tr>
<tr>
<td>6. Rebecca#</td>
<td>&lt;$30,000</td>
<td>Year 10</td>
<td>Australia</td>
<td>De facto</td>
<td>Parents, one child aged 10</td>
</tr>
<tr>
<td>7. Jane</td>
<td>&lt;$30,000</td>
<td>Year 10</td>
<td>Australia</td>
<td>Single</td>
<td>Mother, one child aged 5</td>
</tr>
<tr>
<td>8. Tessa#</td>
<td>&lt;$30,000</td>
<td>Secondary</td>
<td>Eastern Europe</td>
<td>Divorced</td>
<td>Mother, one child aged 12</td>
</tr>
<tr>
<td>9. Frances#</td>
<td>&lt;$30,000</td>
<td>Post-secondary</td>
<td>Australia</td>
<td>Single</td>
<td>Mother, four children 16, 15, 8, &amp; 11 months</td>
</tr>
<tr>
<td>10. Carter#</td>
<td>&lt;$30,000</td>
<td>Year 4</td>
<td>S-E Asia</td>
<td>Separated</td>
<td>Mother, one child aged 13</td>
</tr>
<tr>
<td>11. Liana*</td>
<td>&lt;$30,000</td>
<td>Post-secondary</td>
<td>Australia</td>
<td>De facto</td>
<td>Parents, two children 7 &amp; 11 months</td>
</tr>
<tr>
<td>12. Helena #</td>
<td>&lt;$30,000</td>
<td>Year 7</td>
<td>Australia</td>
<td>Divorced</td>
<td>Mother, two children, 15 &amp; 11 years</td>
</tr>
<tr>
<td>13. Peter*</td>
<td>-</td>
<td>-</td>
<td>Australia</td>
<td>De facto</td>
<td></td>
</tr>
</tbody>
</table>

Notes: Members of the same family as shown*. Participants 4-12 were living with mental illness. Participants shown with # lived with a child with mental illness.

The income of each family was less than $30,000 per annum, compared with the average annual income of $28,444 for sole-parent families with dependent children in 2009-
2010 (ABS, 2011b), and the $44,096 average annual income for all households in Australia at the time the study was conducted (ABS, 2011b). Five families lived in their own homes and six in either public or private rentals; one did not specify her housing arrangement. One participant had completed her secondary education; three had completed year seven, and another three, year 10; four had gone on to post-secondary school education; and one had completed year 4 in South-East Asia. Two participants had been born outside Australia, for whom English was their second language, and one identified as Aboriginal/Torres Strait Islander.

As shown in Table 8.2, adults in the households included parents, grandparents, a foster parent, and, in one household, another adult family member. There were 16 adults, 12 women and 4 men, in the 12 households, aged between 21 and 75 years. The households included 22 children, 12 boys and 10 girls, aged between 11 months and 16 years. Seven of the children (31.8%) had a mental illness (see Table 8.3), with four boys aged between 8 and 12 years with Attention Deficit Disorder (ADD), with one also having PTSD, and three girls aged between 13 and 16 years with depression, or anxiety and depression.

**Table 8.3: Mental illnesses experienced by children and adults**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number affected</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td><strong>Number affected</strong></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td><strong>Adults</strong></td>
</tr>
<tr>
<td>Attention Deficit Disorder (ADD)</td>
<td>(boys) 3</td>
</tr>
<tr>
<td>Attention Deficit Disorder and Post Traumatic Stress Disorder</td>
<td>(boy) 1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-</td>
</tr>
<tr>
<td>Anxiety and depression</td>
<td>(girls) 2</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>-</td>
</tr>
<tr>
<td>Bipolar and Borderline Personality Disorder</td>
<td>-</td>
</tr>
<tr>
<td>Depression</td>
<td>(girl) 1</td>
</tr>
<tr>
<td>Depression and Borderline Personality Disorder</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>7</strong></td>
</tr>
</tbody>
</table>

* Male, the other adults are female.
Ten of the adults (62.5%), nine mothers and one adult family member, aged between 21 and 51 years, had a mental illness: one with anxiety, two with anxiety and depression, one with attention deficit disorder, one with bipolar disorder, two with bipolar and borderline personality disorders, two with depression, and one with depression and borderline personality disorder. Hence the group of families studied lived with a complex combination of issues, including low income, potential housing insecurity for those in rental accommodation, parenting responsibilities, and mental ill health.

**Family workers demographic and employment information**

*Table 8.4: Family workers demographic and employment information (n=9)*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>FT/PT</th>
<th>Position</th>
<th>Qualification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Geri</td>
<td>Female</td>
<td>51-60</td>
<td>Part-time</td>
<td>Project Worker</td>
<td>Gestalt Therapy</td>
</tr>
<tr>
<td>2. Jenny</td>
<td>Female</td>
<td>41-50</td>
<td>Part-time</td>
<td>Mental Health Family Worker</td>
<td>Diploma in Counselling</td>
</tr>
<tr>
<td>3. Lesley</td>
<td>Female</td>
<td>41-50</td>
<td>Part-time</td>
<td>Project Coordinator and Mental Health Family Worker</td>
<td>Bachelor of Social Science; Diploma in Community Welfare</td>
</tr>
<tr>
<td>4. Mark</td>
<td>Male</td>
<td>31-40</td>
<td>Part-time</td>
<td>Team Leader</td>
<td>Social Work</td>
</tr>
<tr>
<td>5. Melanie</td>
<td>Female</td>
<td>41-50</td>
<td>Full-time</td>
<td>Aboriginal Family Worker</td>
<td>Life skills in welfare/counselling</td>
</tr>
<tr>
<td>6. Natalie</td>
<td>Female</td>
<td>31-40</td>
<td>Part-time</td>
<td>Mental Health Family Worker</td>
<td>Social Work</td>
</tr>
<tr>
<td>7. Ruth</td>
<td>Female</td>
<td>51-60</td>
<td>Part-time</td>
<td>Mental Health Family Worker</td>
<td>Psychology</td>
</tr>
<tr>
<td>8. Sam</td>
<td>Male</td>
<td>41-50</td>
<td>Part-time</td>
<td>Mental Health Family Worker</td>
<td>Social Science (Counselling)</td>
</tr>
<tr>
<td>9. Tanya</td>
<td>Female</td>
<td>41-50</td>
<td>Full-time</td>
<td>Aboriginal Family Worker</td>
<td>Community Development; Aboriginal Studies</td>
</tr>
</tbody>
</table>
The family workers completed a brief questionnaire which gathered demographic and employment-related information (shown in Table 8.4). Seven of the mental health family workers were women (78%), with six aged over 41 years, and five working part time in their family worker role. Two of the women were Aboriginal family workers, contributing to the agency’s commitment to culturally and spiritually sensitive practice. The family workers held a range of qualifications, including social work, psychology, community welfare, and community development.

Lived experience of mental illness

Mental illness was a constant presence in the lives of the families, not only for the family member with a diagnosis, but also for the whole family. Having a diagnosis, controlling symptoms, accessing medication, complying with treatment, and dealing with social attitudes affected family life in predictable and unforeseen ways. Lack of knowledge about mental illness and its management, and stories of recovery journeys were all part of the respondents’ experience.

‘It’s with me but it’s not me’

Liana was adamant she was not her diagnosis; her diagnosis of bipolar described her mental illness but not who she was as a person: ‘my illness is a part of me and it always will be, but it’s definitely not me’ (Liana – interview 2). Making this distinction was important to Liana. She was emphatic that she did not want to be identified as a person with a mental illness: ‘I would hate to be known [as] … the tall blonde girl who has bipolar’. She accepted that she had a long-standing and fluctuating mental condition, showing that she understood the implications of living with her mental illness.

Frances recounted her relief at receiving the ‘right diagnosis’ of anxiety after having been told for many years by general practitioners and counsellors that she was suffering from depression:
No I’m not depressed [but I was ending up depressed] because I’d feel so helpless … I’d try and get help and people would tell me I’m depressed … after so many times of being told you suffer with depression, it’s like well maybe I do, maybe I just have to accept that, maybe I’m in denial. When I was diagnosed with an anxiety disorder the penny dropped and I just got this amazing peace, and I just thought, yeah that’s exactly what it is (Frances – interview 1).

Family worker, Melanie, noted how people did not always react as positively (as Frances did) to receiving a diagnosis, but most experienced some relief. As Frances put it: ‘At least I know what’s wrong with me now’. For some a diagnosis is an obstacle. As Melanie noted: ‘It can hold them back … and put them in a place where the fact that they’ve been labelled is stopping them from being able to move forward’.

‘It hurts, it really hurts when people use language like that’

Most of the parents and carers did not use the word ‘stigma’, although their responses were consistent with experiencing the stigmatising attitudes of others. The mothers spoke about how their mental illness, or the diagnosis, affected the way other people reacted to them and how they interacted with others. They spoke about disparaging and mocking language; people distancing themselves from them; and the way this affected their own sense of self and identity. They talked about the negative attitudes of strangers, family members, and neighbours towards mental illness, often dismissing these as a lack of knowledge and understanding. They described how concern about how others might react influenced how they explained mental illness to their children, and this influenced their decisions about whether or not to seek supportive services.

Liana described her experience as an 18-year old, following a six-month stay in a psychiatric unit. Soon after her discharge, she was speaking to a girl in a shop who asked her whether she would like to go to a party that night:

All I had known for the last six months was psychiatric wards, so I didn’t really have anything else to talk about, and I found out later that the girl couldn’t sleep next to me because she thought I was going to kill her. So there was a lot of stigma when I was
18 and I went into the psych ward in year 12, and people just thought, ‘oh God she’s, you know, she’s schizo, she’s psycho, she’s this, she’s that’ ... it hurts, it really hurts [when people use language like that] (Liana – interview 1).

Sole-parent Jane described the upsetting use of language towards her by her son’s father:

[He says] negative things about me to him, and he already has done, over the years, he’s done the, oh you know, ‘your mum is cuckoo’, you know, does this weird call and then sometimes [my son] has copied it (Jane – interview 1).

Jane felt anxious about her future relationship with her son and wondered whether he would respect her, saying that her son’s father:

Seems to have grown up not having a real healthy respect for his mother and, yeah it’s just feeling that I, and I really love and adore [my son] and I do, I’m not the best, you know, there’s no perfect parent (Jane – interview 1).

Rebecca described her perceptions of her neighbours’ lack of knowledge and understanding of her and how she had distanced herself from them, leaving her feeling unacknowledged. In time, Rebecca took corrective action:

I’ve been here for four years and its taken four years for two of my neighbours to speak to me, because they did not understand what I was going through, and what my mental health problems are. Now they understand and they all talk to me, but it took them all that time. They just looked at me as the mad idiot across the road (Rebecca – interview 2).

Rebecca said her neighbours had not spoken to her to begin with because she:

Used to yell and scream and carry on ... I was a ranting and raving idiot, and they had every reason [not to speak to me] but no-one ever said ‘are you alright love, what’s the problem, why are you being like this’. They just said ‘that lady across the road, there she is again’, and that, that really upsets me (Rebecca – interview 2).
The neighbours had changed their attitudes towards her because: ‘I changed my ways, through the yelling and screaming and stuff like that, yeah’. Their acceptance of her was experienced by Rebecca as:

Very positive … and a real big weight lifted off. There’s nothing worse than walking out your gate and having a neighbour that doesn’t like you … it’s not a nice feeling that anyone [is] disliking you (Rebecca – interview 2).

One of the neighbours had spoken to others and:

Filled them in a bit more about what the problems are, and other neighbours then came and supported me … so I didn’t think I’d ever have that support. [Rebecca continued] this change had been my work. It hasn’t been Mental Health’s work. It’s all been my work (Rebecca – interview 2).

Elizabeth’s negative experience with her neighbours arose from the uninhibited behaviour of one of her children on occasions:

These neighbours here all hate me, they don’t like me because of [her child] … it’s really hard living around here sometimes when you know that they all stick their noses up in the air whenever they see you (Elizabeth – interview 1).

‘It can be exhausting trying to get yourself respected’

Participants described their ongoing struggle for acceptance, their negative self-concept, and feelings of isolation. Seeking to be included and acknowledged can be exhausting, with people sometimes isolating themselves when they most need to feel understood and accepted. From her perspective as a parent Frances commented that:

There is still a lot of stigma out there … and it can be exhausting, trying to identify with others, explain yourself, trying to get yourself to be respected or put on equal standing, and to have your mental illness acknowledged, and not be set apart negatively … what seems to happen is people get exhausted or drained, and they isolate themselves … it would be lovely if that stigma wasn’t there so much, so that it wasn’t such a battle (Frances – interview 2).
Frances believed that withdrawal from social interaction was not healthy as:

The very thing … a person with a mental health issue needs is that support and being in a peer group, and they end up without one …. self-help groups for parents would be helpful, where they would be accepted for who they were, and have support, and that hope and that encouragement about where they’re at (Frances – interview 2).

Family worker Melanie discussed the association between isolation and stigma. She believed that some families were grateful they had someone (a family worker) to talk to. Family worker Jenny said:

I think some people are fairly socially isolated … especially struggle with mental health challenges and because of the nature of stigma around that too they’re sort of limited in who they can talk to about their issues (Jenny, FW).

‘I don’t know who I am any more’

Family worker Lesley believed negative perceptions led to a loss of sense of self, and it was important to work with parents to develop, or restore, their positive views of themselves, and help them to find a way forward. How they saw themselves with their ‘mental health difficulty’ determined ‘how they see others viewing them’. It was important to Lesley that she provided parents with opportunities to create more positive stories about themselves, to think about themselves differently, to allow ‘those other stories about themselves’ to be told. She described one mother’s ‘real sense of disconnection from herself’ and recalled her saying:

‘I don’t know who I am anymore … I just don’t know who I am and I really need to know who I am in order to get my life back in order, but I don’t know where to start’. I [Lesley] went away and thought about it, and I thought well, well one thing I do know is that she values the importance of getting to know herself, something about her, and I went back to her and I said, ‘look I was just thinking about this, I was thinking, you know, you’re letting me know about how you don’t know who you are anymore, and how important it is for you to know who you are, and I’m wondering … is that something that you actually know about yourself that you value, knowing
who you are and that you also know that you’re on this journey of getting to know more about who you are (Lesley, FW).

Lesley believed this question was significant for the mother, enabling her to convey:

Stories about what she valued and what … she wanted in her life … to come to life … and form that bit of a picture about where she was heading (Lesley, FW).

‘I’ve talked to her about it right from the word go’

The participants talked about the difficulties they experienced in explaining a mental illness to their children in an age-appropriate way. Liana was concerned about how her young daughter would explain her absence from the school playground to her peers, when she was in the psychiatric unit:

If I had been in hospital with a broken leg from a car accident … she could say ‘yes mummy’s in hospital because she’s got a broken leg’, or something like that, but for her to explain to children who were seven years of age that ‘mummy’s in hospital because she was … going nuts’ she [would find it] really hard (Liana – interview 2).

Liana thought her daughter found it ‘really difficult, really, really difficult, but her and I talk, you know, she understands … that it’s with me but it’s not me’. She had offered to attend her daughter’s class to answer questions about her mental illness:

I went up to them [the school] and I said to the teacher, ‘if any of the kids have questions to [her daughter] and she can’t answer them, I would like it if they can all come and sit in a group and you can say, ‘right, you know, what are these questions that you have for [daughter], can I help with answering them’, because it’s you know, isn’t talked about with children, and especially with children who, they may not have a parent with mental health, but it’s still a very big part of their world (Liana – interview 2).

Since the mid-1980s, there have been public education campaigns to inform the community about, and reduce negative attitudes to, mental illnesses. Helena did not believe
these campaigns had achieved the intended outcomes, because most people turned a ‘blind eye’ to mental illness; they did not understand it and never would. Mostly, ‘mental illness is just pushed to the side’ (Helena – interview 2).

Mothers differed in their motivation and approaches to talking about their illness with their children, with one mother alerting her child not to talk outside the family about mental illness. Liana and Jane had children of approximately the same age and their different approaches were influenced by their level of confidence, and the influence of others. In the week before the research interview, Liana had been admitted to a psychiatric hospital. She described the way she explained her hospitalisation to her seven-year old daughter using the analogy of the brain being a puzzle which:

Comes apart, and it is very difficult to put it back together. [At home, Liana’s daughter] sees me take medication and stuff, and she’ll ask what it’s for, and she … understands it as best as she can for her age … I’ve talked to her about it right from the word go (Liana – interview 2).

Liana said her approach was not to tell her young daughter everything, but she created opportunities for her to ask questions from time to time.

Jane described her young son’s awareness of her frequent visits to the doctor. He would say things like ‘oh … you’re going to the doctor again’, and ‘oh, gee, you see Dr B a lot’. She continued: ‘I’ve never felt like I can explain to him. I think sometimes I’ve said I feel sad’ (Jane – interview 1). Jane wanted to foster a ‘positive bond’ with her son and her approach was influenced by the behaviour of her child’s father towards her, and her mental illness, which she had experienced as negative, as described earlier.

Sometimes explanations by mothers to their children about the effect of mental illness on their behaviour helped to explain past behaviour. Since receiving a diagnosis and starting to take medication, Frances had become open with her children about her irritability. She said previously she might have said: ‘deal with it, you know, this is the way I am for three days’ (Frances – interview 2). Frances’s new approach was to explain that:
It’s unreasonable that I’m this irritable, and it’s because I’ve forgotten to take my medication. When I’m taking my medication and I’m consistently taking it this won’t happen (Frances – interview 2).

Frances believed that an advantage of explaining her anxiety and treatment to her adolescent son was that he could ‘let some of his worries [about me] go’. Alongside being open with her children about her mental illness, Frances felt she needed to ask her younger son not to talk about it outside the family:

I’m constantly saying to him (her younger son) because he’s so very open about things, constantly saying to him, ‘you mustn’t talk about our business outside of the family because people do take things the wrong way and not everyone needs to know everything’, so constantly saying that to him, and then trying to get him to understand it (Frances – interview 2).

Sometimes professionals became involved in helping children to understand their parent’s mental illness. Practitioners working with Rebecca’s son were ‘starting to do that with him now, to understand mum’s mental illness, so that’s still what they’re doing on him right now’ (Rebecca – interview 1). As Beth, a grandmother caring for her grandchildren said, while their mother was in hospital she had told them ‘that mum’s just had to go into hospital for a little while, and they’re satisfied with that, and then they talk to her on the phone and that’ (Beth – interview 1).

Children are affected in many ways by a parent’s mental illness: Sometimes they had to take on extra responsibilities and cope with unpredictable behaviour, especially if a diagnosis and effective treatment was not in place. While Helena’s children were very aware of her illness, as she had talked about it with them, she said:

The impact on children isn’t very good. I can tell you that now. My daughter has had to pretty much raise my son because of my borderline [personality disorder], and my daughter’s 15. My daughter yeah she’s had to, you know, look after [her brother] while I’m in bed not well, and she should be at school, he should be at school (Helena – interview 1).
Diane and Jane both lived with anxiety, and were aware of its effect on their children. Diane explained:

It was affecting my son, because I don’t really want to leave the house much and I realised it was impacting on him, he wasn’t wanting to leave the house (Diane – interview 1).

Jane, too, worried about the effect of her anxiety on her son:

And it’s a worry to me because there’s times where I go through stages where I’m all anxious and I worry about my anxiety rubbing off on him, and I think that does happen sometimes and it’s probably inevitable because it’s just him (Jane – interview 1).

She had sought advice from the mental health service she was using and had been referred yet again to another service, with no follow up.

Frances said that her children had been affected by her mental illness until she had received a diagnosis:

For many years it (mental illness) really impacted on the way I parented and I think … my parenting was awful really, so just really highly strung, really irritable and … always on their backs, you know … not knowing what the anxiety was, not being diagnosed at that time and then, yeah, just the effects on the kids (Frances – interview 1).

Without a diagnosis Frances had not received treatment of any kind, so it was a relief to eventually know what her problem was and to receive ongoing counselling and prescribed medication. She described herself as a different person:

It was like a miracle, like my kids are just in shock, you know, like it was just, I was just so calm, you know, just so level and balanced and calm, a completely different person, like amazingly so, like I can’t, I don’t think there’s words to describe the difference to who I am now (Frances – interview 1).
Just as the symptoms of a parent’s mental illness may impact on children, the emotional and behavioural problems of a child with a mental illness may impose consistently stressful demands on the parent or carer, straining the parent-child relationship, and other relationships in the family. Tessa’s young son was receiving treatment for mental illness, and parenting him was very difficult in comparison to his older siblings. She said:

It is very, very hard to get him to do stuff. We have to make the plan, every single day he has written on the paper what he has to do at mid-morning … because I was all the time yelling and screaming in the morning, ‘get dressed, get dressed, do your bed, brush your teeth’, every single morning (Tessa – interview 1).

Tessa found managing her son’s behaviour relentless:

I have to do it, I love him, he is my son, it’s not easy job but I’m trying my best to help him too, and do the best … but it’s hard lots of the time (Tessa).

Claire, who cared for a foster child with anxiety, noted he became distressed in crowded environments, which affected the family:

I feel my kids have missed out on things, because say, we don’t go to the movies because he can’t handle the crowds, and sitting in the movies, things like that, so we just don’t go, or you know … we don’t go on the train… like we used to in the holidays, things like that because he just can’t handle it (Claire – interview 1).

Alex recounted how her life had suddenly changed when she started caring for her infant granddaughter: ‘I went to work one morning and came home with a twelve-day-old baby’ (Alex – interview 1). I felt ‘isolated, because you know, your life is restricted anyhow with a school-aged child … I do chaff at that bit … occasionally … the loss of freedom … and the loss of my, well, autonomy’ (Alex). Alex had to fulfil the parental role:

I do the gym thing, and I’ll be doing the swimming thing because she’s now decided she wants to go back to swimming. It wears me out … and trying to organise dinners that can be sort of plonked on the table in ten minutes, just about every night of the week is quite a challenge (Alex – interview 1).
She also experienced stress, at times, having to manage her granddaughter’s very challenging adolescent behaviour, including relentless verbal abuse, which she found ‘unbelievably … difficult’. At one point she wanted to relinquish her caring role. Alex’s experience showed how her daughter’s mental illness had led to profound experiences of loss and grief that is not always recognised, acknowledged, or articulated. As Alex recounted, she wondered what she had done wrong:

What did I do, what didn’t I do [in relation to raising my daughter], and um, I think yeah, it has certainly caused me very real grief in looking at myself and as a mother … it’s not a grief that you can acknowledge once and place it with great love and tenderness in its coffin and say goodbye … It’s always there (Alex – interview 1).

Alex thought that her daughter’s repeated admissions to a psychiatric unit would be easier for her (Alex) over time, but they were not. Instead she relived the grief of the loss of the potential in her daughter, ‘in this, you know, baby that you’ve carried, the child that you’ve reared’. Alex thought her granddaughter might also feel a sense of loss that she did not have a close relationship with her parents: ‘She doesn’t enjoy seeing my kids and their families (cousins), [and this was] probably painful for her, to see what she does not have’ (Alex – interview 1).

‘I just thought I was a really bad mum’

Most of the participants had themselves received very little, or next to no information about mental illness, whether their own or that of a family member. Several of the mothers described how they either did not know they had a mental illness, or did not understand the diagnosis they had been given; some understood their illness, but had little confidence in clinicians treating them. Frances recounted:

I was frightened to ask for help. I never considered I had a mental illness, I just thought that I was a really bad mum and that’s all there was to it so, you know, I didn’t say anything to anyone based on that fear. I was scared that my children would be taken off me and, yeah, it never occurred to me, you know, that that wasn’t normal. I just thought oh well single mum, it’s tough and I have to do it (Frances – interview 1).
Diane said she was just beginning to learn about her mental illness:

I’ve got this thing, it’s just a weakness, I’m learning … that’s common … I’ve always been told I had depression anxiety, but I just thought it was, you know, just something that the doctors tell you. [Doctors] I had in the past have just thrown me antidepressants (Diane – interview 1).

At the time of the interview, Diane had a different General Practitioner who:

Had me wanting to work on my health and everything, when before I didn’t really, [I] gave up smoking cigarettes and everything … she showed that she actually cared … I felt comfortable, she made me feel comfortable (Diane – interview 1).

Liana said she had been diagnosed with borderline personality disorder when she was 18 and stated:

I still to this day don’t really understand what that is … when I was in hospital … what I remember of it, are different medications, [I] wasn’t told what medications they were. If I didn’t like them then they’d just put me on another one, but I was never told what they were. There were no therapy sessions … I left [the hospital] … I had a counsellor for a little while … but once he had left … I was on my own again … I [had] a good eight years I think … without taking the medication (Liana – interview 1).

Helena knew what her diagnosed mental illness was, stating that:

No-one understands borderline personality disorder … everyone knows about bipolar, whereas you talk about borderline, no-one knows about borderline, they just look at you and go, ‘well what’s that’, and to sit there and explain borderline is really hard … I can’t explain it (Helena – interview 1).

She had clear ideas about the treatment that worked for her:

Medication doesn’t treat what I’ve got. It can help it but it doesn’t treat it … I needed proper therapy. I didn’t need just be pushed and handed over to a therapist that had no
idea, which I was … I needed proper psychotherapy (for borderline personality disorder) (Helena – interview 1).

‘Chin up, you’ll be right’

Families, too, had very little knowledge about mental illness. Liana said her partner’s family didn’t:

Know a lot about mental health, so that was really, really difficult for me, really difficult, and that one family member had sent her a message saying ‘chin up, you’ll be right’, ‘build your bridge’… I was thinking, ‘I want to do that’, yeah, and then you have that thing where you think, ‘I’m just going to be what they want me to be’… So I’m just trying to educate them more (Liana – interview 1).

Another family member compared Liana negatively with someone else they knew who had depression and ‘who doesn’t behave like you’ (referring to Liana). While Liana did not feel fully informed about her mental illness, she realised that rather than be ‘what they want me to be’, she would try and make them understand, and educate them about mental health issues, so she gave them an information pamphlet, which they read (Liana – interview 1).

Young people generally want to know what is happening to their parent when they have a mental illness but they may not be given the relevant information either by their parent, or the professionals involved (Cooklin, 2004). Scott, an adolescent family member, had two family members with mental illness, and he wondered how a mental illness affected someone’s behaviour: ‘what it (mental illness) causes … like … so like what it does … sort of like the stuff it makes people do’ (Scott).

Claire had been informed by the child protection authorities who had placed the child in her foster care that he had post-traumatic stress disorder, but she had not been given information about the causes or symptoms of his disorder, or how to manage it. She had been advised ‘if he can’t handle going to the shopping centres, don’t take him’ (Claire – Interview 1).
‘I needed help…I was honest’

Symptoms and behaviours associated with mental illness put strains on family relationships. Beth and her husband began to care for their daughter’s three children when the youngest was a baby. Beth said she had some learning to do, but ‘it didn’t take me long to learn’. She believed the children were ‘lucky that they’ve got their grandparents to [look after them]’. While committed to caring for her grandchildren, Beth experienced conflict with her daughter, their mother, who used alcohol and drugs, demanded money from Beth, and damaged her property. Beth also felt constrained by her daughter’s behaviour, saying:

[although] it’s my home, I don’t feel like I can do things, I should be able to do what I want, see who I want [at home], but then I think [that will be] just some other little thing that she can have a pick, pick, pick at [when she hears Beth has had a guest]. It’s always targeted at me because I suppose I’m the only one that’s around (Beth – interview 2).

Beth had explained to a friend that she could not visit as her daughter did not like her:

They almost had a few words once too, and I would have been uncomfortable if [friend] was here because I kept thinking that if [daughter] saw her here she could start the thing, I didn’t want to embarrass her and things like that (Beth).

The reality of a lack of continuity of relationship with her granddaughter, who lived with her, was on Alex’s mind, as she thought about her own mortality. She recognised she would not be alive to support her granddaughter through her life, saying:

I’m not going to be around … I’ll be doing well if I make it to eighty … The realistic thing is that I’m not a parent. I’m not going to be around as long as a parent … I’ve mentioned this to her a few times … ‘always remember … there’s help out there’, you know, because, I said, ‘I’m not going to be here as long as a parent is’, and that upsets her to hear it, because I’m not allowed to die, she said to me, ‘you’re not allowed to die’ (Alex – interview 2).
Like Alex, several mothers had experienced difficulties in their relationships with their children. Apart from living with mental illness, some had to deal with the mandatory child protection authority. Tessa had been concerned about the behaviour of her primary school-age son, which was very stressful for her to manage. He had threatened to hurt himself on one occasion, and on another she had hit him because he would not go to school. She had rung the child protection authority herself, saying to the worker:

I smacked him because he’s getting to the point [where] I could not cope with him and I really need help … I was honest … if no-one is going to help me that could end up really badly for him or for me (Tessa, interview 2).

Tessa sought support to prevent further deterioration in her relationship with her son. He had laughed at her because she took various tablets, and she tried to explain to him: I need those tablets, they are not like drugs [taken by] people doing the wrong thing (Tessa – interview 2).

Sometimes difficulties between family members occurred that did not directly involve the parent, but had a distressing outcome for the parent. The father of Carter’s daughter had not lived in the home for some time. Following his return, disagreements occurred between father and daughter which led to the daughter being taken from the home and placed in foster care by the child protection authority. Carter said her daughter’s belongings were still in the home, and ‘I don’t know if she [is] sick, so many trauma … my heart [is] broken’ (Carter – interview 2).

Raising adolescent children and having a mental illness that was not being effectively treated placed strains on Frances and her family with tensions in relationships with her son and her daughter. Frances had experienced her adolescent daughter’s behaviour as challenging, describing her daughter as being:

Just a normal, selfish teenage girl, lying her way through whatever to get her own way and … she was hanging out with all these delinquents, and they’re just telling her how to, you know, how to get away from your home basically … telling the [school] counsellor that ‘mum beats us’ (Frances – interview 1).
Frances described how, following an argument with her daughter, she had been placed with her (daughter) father by child protection authorities. These events occurred prior to Frances receiving an effective diagnosis, and treatment. She described herself as ‘being really angry all the time … I’d come home from work and I’d just yell all the time, just yell’ (Frances – interview 1). Frances remained hopeful that, in time, she and her daughter could re-establish their relationship.

‘I’m with it now and I’m actually being a mum’

A parent’s recovery from mental illness may change the dynamics between parents and children. Where a young person might have taken a parental role with younger siblings, or a carer role with their parent, the recovery in health, confidence, and parental authority of the parent might challenge the status quo, as described by Helena. Her daughter had been ‘mum’ to her younger brother for several years, and was also attending school. Helena was getting better, and noted her children were:

Not used to having a mum that is with it, and not sleeping or you know, off her face on drugs … I’m with it now and I’m actually being a mum, and they’re not really used to that, and it’s causing a bit of conflict in our house, but they’re coping with it (Helena – interview 2).

As Helena found confidence through her treatment, she had begun to place limits on her daughter: ‘I’m starting to say no’; she had grounded her daughter for a month. Previously, Helena would not have done this:

I would have just said ‘oh yeah, she’s 16, what do I care’, because I was sick, but I’m not sick now so, you know. [She said to her daughter] ‘you lose your internet, your computer, you’re not allowed to have anyone here, you’re grounded, you’re at school. You come home, they’re the rules mate’ you know (Helena – interview 2).

Following the diagnosis and effective treatment for her anxiety, Frances said she could say to her son:
It’s OK for me to be irritable … I’ve asked you five times to do this and you haven’t, you’ve ignored me every time … it’s not part of my mental illness, like I’m allowed to be angry with you (Frances – interview 2).

Her children were learning that they could not make excuses for their lack of cooperation. Frances felt her irritability was a ‘fair call’, when she had asked for something to be done five times (Frances – interview 2).

Some mothers described their feelings of guilt about their illness and its impact on their children. They needed to be assertive to ‘move on’ from that position. Frances and Helena had reached the point where they no longer felt guilt and the need to apologise for the past, even if their children wanted this. Frances said her daughter was still angry with her, first, because of the argument that had occurred between them, and also because Frances had moved beyond feeling guilty, saying to her daughter, ‘I won’t be locked into the past because of your hurts’. While Frances understood that her daughter remained angry, she believed that she herself had to move on because she had other children to care for: ‘[I] can’t parent these boys well if I stay locked in that [guilt]’ (Frances – interview 2).

Helena thought her daughter had found taking on parental and carer roles while her mother was ill had been difficult, and remembered her daughter asking her: ‘Do you understand how it’s been for me mum? Helena said she had responded:

I can see how it’s been for you and I’m sorry, but I’m well now [and explained to her daughter that she is not going to apologise any more] because I wasn’t well … and I can’t change it … so I have had to learn to deal with it and work on getting myself to a place where I’m, you know, I’m still not a 100 percent, but I am better than I have been (Helena – interview 2).

Reflecting on the experiences of her children, Helena said:

I’ve sometimes thought … they’d be better off without me because I am such a mental case and I am pretty screwed up, but I just think, you know being the way I am has made my kids grow up and really, they know about life.
Helena said she sometimes became distressed when thinking about the responsibilities her daughter had to shoulder while she was unwell: ‘She’s had to put up with a hell of a lot … so you know, I feel sorry I guess, what I’ve done wrong’ (Helena – interview 2).

Conclusion

The findings presented in this chapter described the lived experiences of the mothers, grandmothers and foster carer, who participated in this study. They highlight the family circumstances, the impact of disparaging comments on self-confidence as a parent, the impact on family relationships and roles within the family. Their comments also show the parent’s understanding of their illness, and the need for children to receive explanations and reassurance about what is happening. Experiences of support are presented in the following chapter.
Chapter 9

Findings: Experiences of family support

While Chapter 8 reported on the lived experience of mental illness for the study’s participants, this chapter presents the findings relating to their experiences of family support. It begins with a discussion of the source of support generally received, before focusing on the parents’ and carers’ experience of support from Headin’ Up (specifically) interwoven with family support workers’ perceptions of the families’ experiences of support, the supportive agencies from which the families had sought services, and the broader service context impacting on their experiences. It then ends with an examination of the factors facilitating or impeding access to support. These first-person accounts of the rich experiences and perceptions of parents and carers, and family workers conveyed the complexity of relationships within families, with others, and with, and among, service providers. To provide an objective measure to complement these first-person accounts, several standardised scales were used to measure aspects of family functioning. As with the first-person accounts, these self-report measures drew on the parents’ and carers’ perceptions of their functioning as a family (see Chapter 10).

Source of support: Families first

For most families, naturally occurring family and friendship networks are the first port of call when help is needed and, as discussed in Chapter 4, the availability of support depends on the strength of the relational ties within these informal networks. However, there are times when formal support is needed from professional practitioners and agencies. Several participants in this study, who were not supported by their extended family, turned to their church for support. Some received support from their friends, and several described positive experiences with supportive professionals, such as their doctor or psychologist.
Rebecca received a great deal of support from her mother: ‘mum’s the back-up support for everything’. She had also enjoyed the unfailing support of her partner over many years:

He’s had 12 years of my mental health … he’s the rock, he’s there through it all so, you know, if I need to get to the hospital, he’s there to drive me to the hospital (Rebecca – interview 2).

Liana and her partner Peter knew they could rely on the immediate support of his parents when Liana became unwell. They found this very reassuring:

The first thing we do is ring Mum and Dad, and you wouldn’t even have to ask them twice. Dad would be half way over here before you finished the phone conversation, and come and get the girls so we could then get Liana to hospital and figure out what we need to do from there (Peter).

Peter also valued the personal approach of their family GP, who was ‘much more involved with the family’ than previous doctors and was ‘always willing to go out of her way to give us information and stuff’ (Peter).

Helena had a positive relationship with her mother and brother:

Family was very, very close … If there’s something that’s happened, my family is there straight away … It’s fantastic, you know, my mum and I, we get along great, and my brother and I (Helena – interview 2).

However, Helena’s relationship with her sister was less amicable (and she described her sister as jealous of her):

She likes the fact that I come down with, you know, the mental illness and I get sick and I don’t cope with life. She likes that fact, she loves it. … She doesn’t like [that I’m getting well], she hates it, that I’m well, you know (Helena – interview 2).

Jane had moved ‘closer to family … to get their support’. She was, however ‘a little bit disappointed’ when it was not forthcoming. Her mother was ‘not in the best health’, though could mind her son when she had a day-time appointment, while her sister could mind him
when she had an evening meeting. Jane had wanted to confide in her mother, but attempts to do so had left her feeling guilty:

I can’t put my worries or stress onto my mum because she really can’t handle it … I did that recently and I haven’t been able to shake, like the guilt from doing it to her (Jane – interview 2).

She also had ‘three fairly close friends but they don’t live really close and we just talk on the phone every now and then’ (Jane – interview 1).

Among other participants, support from extended family ranged from occasional phone calls to none at all. Tessa and Carter had no family support as they had come to Australia from overseas. They missed having face-to-face contact with their families.

Carter was not able to speak to her family as they did not have a telephone, but they communicated via the internet. She relied on neighbours for help. She talked about a time when she had been visited at home by people from a bible study group, and said she prayed and talked to her God when she was alone. She could also depend on support from a worker from the migrant support centre who spoke her native language: ‘when there is something, when there’s problem, I only ring N’ (Carter – interview 1).

Tessa was able to speak to her family on the phone but wished she ‘could have family here – I [wish I] could, you know, speak with them’ (Tessa – interview 1). However, she had a valued friend whom she described as non-judgemental: ‘I never had the feeling that [she] was thinking [badly] about me’. She described her as:

A special friend … and she always supports me … we usually see each other weekly or if we couldn’t then every fortnight we meet each other at the shopping centre, or she’s coming over or she’s asking me to her place, and she’s making lunch and we’re spending time together (Tessa – interview 1).

Tessa talked about being pleased to hear her native language spoken when she had first arrived in Newcastle:
I know when I came here I was in a shop when I heard … people speaking … I was so happy to hear my own language because at the time I did not speak English … I used to go every Sunday to church (Tessa – interview 1).

She had joined the church community attended by people from her European country of origin, and experienced ‘having support from [them] at that time’. However, in time, Tessa felt that members of the church community were putting her down because of her son’s behaviour, so she ‘stopped going to church because he was screaming’. She had been ‘so embarrassed … and became very upset [it was] very, very, very difficult for [me]’ (Tessa – interview 1). Once she stopped going to church Tessa lost the cultural, social, and religious support of the church community.

Foster carer, Claire, did not have family members she could call on for childcare for her foster child. This was problematic for her as he could not go out with the family because he became stressed and anxious in crowds. She did, however, have a friend who lived in another city and she sometimes phoned her to seek advice about her foster child.

Frances felt alone, having no support from her extended family. This encouraged her to strive to provide well for herself and her children through her association with community services and institutions. She said her childhood had not been great, and that she was estranged from her family, so she was ‘doing everything on [her] own’. She had ‘made an effort’, and believed that:

You always try to improve who you are so I … go to church and I have a faith, and I put the kids into private schools and … you try and get them in extra-curricular activities and so all the while trying to improve who you are as a person and a parent and improve their lives (Frances – interview 1).

Frances had sought support for herself and her children by going to church but rather than feel supported she felt judged because she was ‘a single mother’. Though she had not received social or emotional support from the church community, she said:

What I do get is more practical support and what I’ve learnt is that I take what I can get, the support I can get, with what people are willing and what they are able to offer
… I might get a meal, or you know, friends I’ve made through the church, I trust them to mind the kids every now and again, you know, so that sort of helps (Frances – interview 1).

Beth and Alex were grandmothers caring for their grandchildren and had friends on whom they could depend and who did not judge them. Beth spoke of her friends who had moved away interstate, or were several hours drive away. However, she could ‘always talk to them [on the telephone] if I wanted to say some things’ (Beth – interview 1).

Grandmother Alex had longstanding relationships with ‘a couple of good, steady friends’, whom ‘I can basically ring ... up any time and just let it all out’ (Alex – interview 1). She ‘had derived a lot of benefit from seeing her [psychologist]’ to whom her GP had referred her when she had become depressed (Alex – interview 2). Alex also attended a peer support group, Grandparents As Parents (GAPS) for grandparents caring for grandchildren, where information was exchanged about financial and other entitlements:

GAPS is wonderful … new people come in … shell shocked … not having a clue where to go, who to talk to … and we sit them down … and say … these are your entitlements (Alex – interview 1).

Diane felt strongly that her GP genuinely cared about her and her child. She:

Had such an impact [on her because] other doctors I had in the past have just thrown me antidepressants. [The new GP] showed me that she actually cared and she wasn’t just another doctor trying to get me in and out of the room. (Diane – interview 1).

Support within their families was available for two young people who both lived with a parent with mental illness. Tom said he could talk to his Mum about his worries, and sometimes his older brother. Scott, a young participant, said he could talk to his sister. He also talked (about issues at home) with his:

Friends sometimes, but like, oh it just like seems like they don’t know what I’m talking about, so I tend not to .... They want to be doing other stuff … I don’t mind, I just put myself in … like, their position (Scott).
The isolation of families from their own families and others, was noted by Ruth, family worker:

Often they’re just really isolated … they don’t have functional families much of the time, they don’t have an extended support system, network of friends that are able to support them in ways that they need to be (Focus group, FWs).

Family experiences of support from Headin’ Up: Relationships first

At the beginning of the first focus group with family workers, Geri described the value of the introduction of Headin’ Up into the Family Support Newcastle service setting. She observed that the creation of Headin’ Up as a mental health team within Family Support Newcastle was of direct benefit to family workers, and this structure was also having indirect benefits for families. Being clearly identified as a mental health team gave Headin’ Up staff internal legitimacy to do mental health work, which had previously only been undertaken by some individual workers in the agency. The benefits to Headin’ Up family workers were that the team structure provided more resources, effective support, and a mental health focus that led to a common language among the team about these issues than occurred within the general family support service. Geri noted: ‘I certainly find it a lot easier to work in that kind of environment than without the internal legitimacy for doing [mental health work] ’ (Geri, FW). She believed that the effect of this acknowledgement for families was that ‘right up front’ people knew that Headin’ Up had a mental health focus, and that their mental health and wellbeing would be taken seriously. This, in turn, ‘opens up the dialogue [between family and family worker] around what wellness and illness means’ (Geri). In the agency structure preceding Headin’ Up, ‘we wouldn’t have been talking about … mental health and wellness in the same way’ (Geri). However, ‘a lot of people don’t automatically present with mental health issues but with related issues and it’s really about the assessment process … and what is the priority’ (mental health issues, financial issues, or other issues):

We examine the situation together in a collaborative way, with the family having choices about their priorities, which may be getting more sleep, or medication being
reviewed, with effective treatment of one issue having positive consequences for other [issues] (Geri, FW).

Geri thus provided an understanding of the context in which the parents and carers in this study had been supported through Headin’ Up and its mental health focus. The accounts of parents and carers speak to the importance of their relationship with their family worker, while the family workers spoke of the reciprocity in these relationships. The parents and carers who were interviewed spoke positively about the benefits of home visits and family workers’ advocacy to, and mediation with, other agencies on their behalf. Of most importance, however, were the relational connections between the families, community, and culture, especially for Aboriginal families, who found a renewed sense of identity and belonging once connected to their community.

Tessa appreciated the family worker visiting her home to speak sometimes with her alone, and sometimes with her and her 12-year old son:

She gave me lots of thinking and advice, like how to cope with him and things like that. At the time [things were] getting better and better so … really I could say [it helped], because, you know, when someone is … saying to you how to deal with the child … I read a few books but it’s not the same, like the people who are educated and they know, they meet lots of other different children, every child is different, and they’ve got experience, so yeah they were helping me (Tessa – interview 2).

Tessa really trusted her family worker, and felt she could be open with her. Her son, who mostly kept things to himself, was ‘happy to speak with [her]’ after he got to know her. Tessa felt the family worker was a ‘good influence on [her son] because after she left he was much better’. Tessa was happy for her son, because he opened up to the family worker, and she could see a difference in him: ‘really I could honestly say there was [a difference] when [my son] was speaking with her and there was some changes’ (Tessa – interview 2). Tessa thought it would have been:

Pretty hard, very hard, if she had not had a family worker, because the person is coming to your house and speaking to you and to your child, and trying to [tell him] what is
right, [and] what is wrong, … and will speak about sport and encourage him, because he doesn’t want to do any sport, now he’s doing the trampoline this year … that is good to have some connection with people (Tessa – interview 2).

Rebecca believed her relationship with her family worker was key to her progress:

[The family worker] helped me in heaps of ways … by getting me through the bad times … those suicidal times and everything … I said to her I don’t know what I would have done without her … she was a big rock and she was a lot of support and help for me … She had a lot of information that could help families, and … she let you know about all the information. You didn’t have to ask her where to go and that … I don’t think I’d be sitting here talking to you now if it wasn’t for [her], yeah … I’d either be in hospital or medicated or lost it (Rebecca – interview 2).

Rebecca had developed a trusting relationship with her family worker though, at first, she had been hesitant: ‘As soon as I see a person, I’ll speak to them or I won’t … but then she was right, I let her in and … everything went well, but it does … really depend on the actual person’ (Rebecca – interview 2).

Diane was also hesitant at first: ‘It took me a bit to let her in’. She had thought the family worker was there ‘to sort of, look into my life and judge me, and stuff like that, at first’ (Diane – interview 1).

Helena said had she not become a client of Headin’ Up, ‘I wouldn’t be sitting here talking to you … I wouldn’t be here, I’d be dead’ (Helena – interview 2).

Liana spoke of her positive experience in a Headin’ Up group for parents that combined groupwork and individual counselling. Prior to her involvement with Headin’ Up, Liana said: ‘it was just me crying all the time … and [I] just sort of wasn’t really here, there was a lot of distance between us’ (referring to her relationship with her young daughters) (Liana – interview 2). She had learnt new coping strategies and had also gained confidence:

I hate to say, but I probably wouldn’t be here today. I would be here but I just wouldn’t be where I am. I wouldn’t have enrolled in college … I probably would have been
hospitalised again. It has saved my life, and it’s allowed me to be the mother I want to be and that I’m meant to be (Liana – interview 2).

Liana’s partner, Peter, believed they were ‘a lot more informed’, through working with the family worker: ‘they had given Liana a lot of coping strategies which she’s working on, which is definitely working as well … So for that reason it’s been really good for all of us’ (Peter).

For Grandmothers Alex and Beth caring for their grandchildren, involvement with Headin’ Up was also positive. They felt they could trust their family worker as someone to talk to, which was important to both of them, especially since they were reluctant to confide in others. Alex explained:

It was just so helpful to me just to talk to somebody … just talking about things that were bugging me or worrying me … I looked forward to her [the family worker] coming … it was marvellously valuable and … such a reinforcement of the power of having someone to talk to (Alex – interview 2).

Beth said, ‘I’m not one to go and tell anyone my troubles’. But Beth found she could talk to the family worker about ‘what I was concerned about’. She felt when she phoned the family worker that she would receive the help she needed. She was sometimes concerned about aspects of her adult daughter’s mental illness, such as mood swings, and would not talk about this with anyone else, but felt she could trust the family worker to maintain her privacy, and provide information and reassurance (Beth – interview 2).

Frances’ feelings of isolation had decreased with the involvement of a family worker:

So I’m wanting that support … just someone that can offer me a sounding board. Feeling isolated in society. Just feeling so different and having to put on a, how do you say, a façade, and not being able to be real, that I think is huge. It’s about being able to just say, ‘you know what, I had a really shitty week’, or ‘I’ve had a great week’, or you know, it’s about giving new ideas and giving you motivation and, you know, I will speak to my worker and I might have questions and, you know, they might be in a position to say, ‘well I’ll find out for you’, you know, it takes away some fears, so
in the past … I have got my support worker to ring up [the child protection authority] and question them hugely, on anything they might have on me, or my children (Frances – interview 2).

As well as their mediation and advocacy on behalf of families to community-based agencies, family workers sometimes interceded with government departments. As Frances has described, her family worker had made phone calls to the child protection authority on her behalf, which she had appreciated: ‘when I’ve tried to ring them [myself] they get really funny, and depending on the worker, they get really rude, and so it’s not worth it’ (Frances – interview 2).

Claire also appreciated her family worker’s intervention with the government department in relation to the foster child in her care. Although she would have persisted herself, if necessary, Claire also said sometimes ‘you just give up’ trying to reach the child protection workers. Having a family worker ringing the child protection authority on her behalf made it ‘more official’, and therefore easier for her to get the answers she needed (Claire – interview 2).

The positive experiences with their family workers were offset by disappointment for one mother, and matter-of-fact attitudes of others about Headin’ Up. Tessa felt disappointed when the family worker ended the service to her family:

[Tessa felt] awful, because [her child] really liked her, he really liked her. It’s not like he could accept anybody, but he really liked her. The first time he met her he said, ‘Oh she’s very nice’, so he was quite happy and he wanted to speak with her … It’s very, very difficult to get him to … speak and be open … he’s keeping mostly things to himself … but after a while [the family worker] got him to say something (Tessa – interview 2).

Tessa said that the positive influence of the family worker on her son was a ‘good thing’ as he was much better after she left.

Alongside the general positive reception of Headin’ Up, some participants felt they would ‘have got by’ without it (Frances – interview 2), or ‘it wouldn’t have made any
difference’ if it had not been involved (Jane – interview 2). Elizabeth felt she would have ‘survived’ without the counselling support provided by the family worker. While these mothers believed they might have managed without Headin’ Up, each qualified their statements. Frances said she would have ‘got by’, but ‘I don’t think I would have grown the way I have’ without the services of Headin’ Up (Frances – interview 2). Jane said she found her interactions with two family workers ‘good’ and ‘helpful’. Elizabeth appreciated having someone to talk to who was not close like a family member, and said it was ‘nice to have that person there to talk to … it’s a good service for people who don’t have many people around them’ (Elizabeth – interview 2).

Referrals and access to other services

The Headin’ Up family workers, general practitioners, and others, including families themselves, referred families to other services when necessary. Some participants were appreciative of referrals to services and groups which were supportive, informative, or related to their personal development. Others had not wanted to attend activities or groups.

Support groups and services accessed were either community or home based. Alex attended a group for people who had a family member with a mental illness, which gave information about mental illnesses, and gave participants strategies to manage this situation, and not to feel responsible for the mental illness their family member experienced. She also attended a support group for grandparents caring for their grandchildren, referred to earlier. Jane and Elizabeth had used home-based services relating to their children, in Jane’s case to help her develop confidence as a parent, while Elizabeth received practical help with dressing the children in the morning, and cleaning the home.

Some mothers had either self-referred, or had been referred to a treatment program (within Family Support Newcastle) for parents with a diagnosis of borderline personality disorder, who were caring for their dependent children. Participating in this program had been a significant experience for them, with Helena observing that the program participants had not judged one another as they described their personal and family experiences. It helped them to realise they were not alone. The program gave participants the opportunity to learn new
relationship skills, such as how ‘to be assertive, not aggressive, and when to talk to him [partner] about certain things’ (Liana – interview 2). The program also restored the confidence of the parents, helped them to manage stressful situations more effectively, and had positive outcomes for their families, such as Liana’s partner being able to see ‘a big difference with the support that I’ve had’, which impacted positively on him (Liana – interview 2). Two of the mothers had developed sufficient confidence to enrol in technical college courses.

Those mothers not attending groups and activities described their reasons as a lack of confidence, a wish for privacy, no need to attend, and wanting to join, but needing to take the next step. In response to a question about being referred to groups Beth said:

I’m not one to go to things like that. Probably think, oh well, I don’t know what to say or something like that, you know, haven’t got enough confidence probably in myself and just keep it all inside sort of thing, and just think, oh well, it’ll get a bit better (Beth – interview 2).

Rebecca responded:

I’m not one that can go and sit down with a group of ladies and go, ‘this happened to me last week and that’. Yeah, no they wanted me to do it but I wouldn’t … I pulled back. With my illness and that, I like to keep it within my family and with my doctors. I’m not a person that goes to people’s places and have cuppas and talks about the children and stuff like that. So yes, I was referred, but I didn’t take it up (Rebecca – Interview 2).

Claire said she did not need to attend a group, though the worker had ‘mentioned from time to time the different groups they often have, but I just don’t need any of those services’ (Claire – interview 2).

Tessa had received a letter about activities for parents and activities for children, but had not yet participated, saying her child ‘was giving me too much of a hard time so too much was going on’:

I think I should go maybe. Maybe they will give me some ideas, maybe I will meet some other people who are having trouble like with children. And now because I’ve
got an appointment with that Newcastle Family Support I will find more about this, so maybe we could, I could go to the friend group too. So I would like to go maybe, yeah, they will help me because at the moment I’m really stressed a lot (Tessa – interview 2).

**Family support workers’ perceptions of the support provided to families**

Isolation for some mothers was identified by family workers, with their capacity to undertake home visits being pivotal in contributing to the recovery process. Jenny described a mother who would not leave the house, and experienced ongoing isolation. Jenny made referrals to other agencies which were unsuccessful, so she had supported the mother at home for a year, and she was eventually able to return to work: ‘It was the ability to go [to the home] and engage with her in her environment’ that contributed to this change (Jenny, FW).

Tanya described her work with a parent of two children who were also socially isolated. The relationship between this mother and Tanya in the home setting was an opportunity for her to observe the children and reassure their mother:

Like coming into her home, you know, being part of her family for that hour really, because that’s what happens, I become part of that environment for that hour or two hours, however long I’m in the home for, and yeah, you know, just being able to hear her story and, you know, a lot of her story sounds quite normal anyway (Tanya, FW).

Tanya continued:

I said [to her] ’I don’t look at you as a person who has a mental illness because everything you tell me sounds like it could be any family, it could be my family on a, you know, chaotic day or on a good day, you know’... just being able to talk to her and, you know, normalise some of her stuff because she’s isolated, it’s like ‘oh that sounds so normal’.

The mother was finding the parenting of her second child more difficult than the first, as the second was ‘a little terror’, while the first had been ‘easy going’. Through her
relationship with her, in the security of her own home, Tanya could reassure her about her children, and convey that the challenges she experienced as a parent ‘could be [those of] any family’.

Several family workers drew attention to their reciprocity with the families. Ruth commented that ‘it’s not just a one off, but it’s a relationship … ongoing, week in week out we turn up’, also commenting that one family had said to her, ‘you are the only service that keeps on coming’ (Ruth, FW). Melanie said that one family had expressed their appreciation of the continuity of her role by saying, ‘well, we couldn’t have done it without having at least one person hanging in there with us’ (Melanie, FW). The mutuality of the relationship between families and family workers, and the commitment of families to being consistent was also acknowledged: ‘what gets missed is their [the family’s] reciprocity, that they’ve been faithful to the process’ (Geri, FW).

The family workers believed the strength of Headin’ Up was its flexibility in undertaking home visits, addressing a wide range of issues, seeing children and parents together and separately, and persevering with families who struggled to keep appointments. Tessa’s experience of Headin’ Up, described above, captured the flexible and mutual reciprocity of the support she and her son had received: the family worker had visited them at home, and would see them together, and separately, to address family and individual issues.

Responses of family workers suggested that their availability to meet with each family in their home was beneficial in building trust and developing a relationship. This also enabled them to advocate for these families when necessary. Geri and Lesley saw home visiting as a ‘really unique’ aspect of Headin’ Up; it made them accessible to families and enabled them to ‘provide a focused service … that takes into account the fact that they have young children’ (Geri). Jenny (FW) added:

The feedback I’ve had is that families really appreciate someone being able to go into the home, because often that stress of getting out, and getting out with kids, when stress can be a trigger, if that can be avoided that’s really important I think too, as if you imagine working with someone who has just had a stressful journey into the
centre, compared to working with someone less stressed at home who hasn’t … had to face that ordeal (Jenny, FW).

Observations the family workers made in the home could contribute to advocacy for the family. An example was Geri’s experience of receiving a phone call from another agency querying a mother’s perceived lack of compliance with that agency’s requirements vis-à-vis parenting issues. Through her ongoing home visits, Geri had observed ‘a highly skilled parent [who] is ideally placed to continue to have the care of the children’, despite her psychological vulnerabilities. The mother, however, felt immobilised by the stringent requirements being made by the other agency. Geri had concluded that ‘without the insight from a family support perspective, a Headin’ Up perspective, there would have been many more judgements made on a legal level to this mother’s detriment’. Geri was able to mediate for the mother in this situation. Ruth emphasised the importance of remembering that these observations had been made in the context of the relationship between the parent and Geri.

Observations made during home visits gave other family workers the opportunity to mediate on the family’s behalf with other agencies, as Ruth had done:

We’re given an opportunity to … [observe families in their family] context and notice them doing good, and so I’ve been able to say to community services [child protection authority] or the mental health teams ‘well actually I saw them doing this’, how many families are sitting down having a shared meal together (Ruth – FW).

These family workers were able to convey their in-depth understanding of the family’s behaviour, beyond what was being assessed as less-than-adequate family functioning. The family workers valued this role: ‘I think that is something really wonderful that I’ve been able to do, for the reputation or the image or the identity of these families’ (Ruth, FW).

Home visits also enabled family workers to notice when children were ‘doing something really well … to notice and celebrate it’ and to help the parents to notice and acknowledge the child ‘doing good’ at the same time (Ruth, FW). Ruth noted: ‘We are wired for [a] problem focus … we’re wired to see negative threats in our environment so we tend to notice the bad stuff more often’. The family worker’s capacity to be in the home, observing
children and parents doing well, was an opportunity to provide immediate positive feedback and encouragement.

The significant change achieved by some parents was gratifying for family workers to see. Tanya spoke about her role with one mother who had felt extremely depressed and isolated. As a result, she had no idea how her children’s behaviour compared with that of other children their age. From her direct observations, Tanya was able to reassure the mother that ‘children have different personalities … and what works with one might not work with the other’. She was able to offer these reassurances to the mother in the privacy of her own home: ‘like sometimes I, if it’s a nice day, I might say “let’s go and sit outside”, and the children just play outside while we chat’ (Tanya, FW). With Tanya’s support the mother had set three main goals for herself, which included being more social, and this had been achieved through attending a playgroup with her child. She had also progressed to being a volunteer with the agency. Tanya felt the support she had given through regular home visits had had a ‘huge impact’ (Tanya, FW).

Family workers in Headin’ Up had the capacity to work with a range of issues affecting the family, and to see one or more members of the family. They found in their initial conversations with parents about presenting issues, such as child protection or domestic violence, mental health issues were not presented ‘up front’ but frequently emerged as the focus of intervention. Parents frequently described experiences of ‘emotional distress or really challenging lives’, which then led to further exploration to ‘discover more about their wellbeing’ (Mark, FW). While Headin’ Up was a mental health program, the families attending sought help for one or more problems usually associated with difficulties with their children but behind this lay their own struggle with mental health difficulties. Dealing with these meant working with members of the family, including children, adults, or the whole family:

Because [Headin’ Up] offers home visits and a number of appointments each week, and works with the whole family … looking at the family as one system, or it [can work] individually with each member of the family, [making it] very flexible, [it] gives services that some other services can’t give, like some services just focus on carers, or
individual issues. With feedback from families and with what I’ve observed it [the program] really fills a gap (Natalie, FW).

Headin’ Up’s holistic ‘focus around the whole family’ had, with a number of families, ‘significantly changed the outcome [of child protection authority involvement]’ (Lesley, FW). The focus, and mandate, of the child protection authority concerns the safety of children, and the gathering of information that relates to risk factors, whereas the family workers can:

Make visible [the] parent’s skills and knowledge around their children and help them work in that area rather than get caught up with the sense of being failures as parents. That’s been really helpful in terms of … having the children remain in their care (Lesley).

With their in-depth understanding of the situations of the families in the program, Headin’ Up family workers persisted when families were unable, or failed to keep appointments. They valued this aspect of the program, which distinguished it from government programs that lacked flexibility:

We don’t tend to withdraw because they may miss an appointment … we continue to offer the service. There are times where I’ve worked with families where, because of one thing or another, [they] haven’t been available at the [appointment] time and … I think if that was a like a state government based mental health service, they wouldn’t have continued in the service (Lesley, FW).

The role of the family worker was pivotal for some families in facilitating a sense of connection and belonging, and reducing isolation, variously through the agency’s family centre or playgroups. Lesley explained:

One of the things I’ve seen … I work with a mum who is very isolated and has connected with a couple of women through the refuge system, and has maintained a friendship. Part of that maintenance of that friendship with them, even though they’ve gone in different directions, is that they’re connected to Newcastle Family Support Service and, being part of the family centre, and I think that … what they do for each other is just magic (Lesley, FW).
[The children’s playgroup was] kind of like a community that’s been created by us … but what those kids have enjoyed, we suspect, would be the first time that they have felt accepted in a group within a community. All these kids have experienced high degrees, high levels of alienation and bullying and all that sort of stuff. There’s this absolute acceptance for all of them. They’re all entitled to be a part of this group and to contribute to the group and participate in the group. They are all valued members. So they may not laugh at this point in time, and may not have great friendships out in the community or in the school yard or whatever, they are finding these opportunities about building friendships within this group (Lesley, FW).

The family workers helped some parents to trust others and develop friendships and relationships. Tanya’s practical support to a mother in her home had facilitated the return of her children by the welfare authorities. The mother had not sought help with this as she had not known that such help was available. As recounted by Tanya, this mother had said, ‘If I had known that you were here in the first place, I wouldn’t, maybe wouldn’t have lost my children’ (Tanya, FW). With support, the mother had accepted help, and became more confident in engaging with others: ‘and she comes weekly into the Centre, and [it is] like a real big turnaround [for] these families, it’s amazing’ (Tanya, FW).

Aboriginal families valued the Aboriginal mental health family worker’s recognition of their cultural identity. An example Melanie recounted was a pregnant mother who joined a group engaged in the traditional weaving of baskets. The family worker and child protection authority worker did:

A lot of work … [to ensure the baby stayed] in the family … I am fairly sure that without our involvement that may not be [the case], there might have been a risk of care being assumed by community services … there’s hopefulness around what happened (Melanie, FW).

Other family workers observed that this mother’s participation in the group, which was also attended by Aboriginal Elders, had led her to develop a sense of enthusiasm and find a sense of purpose. She had developed the skills, and confidence, to teach basket weaving to
others. Through participation in the group, she had ‘discovered she belonged’ (Mark, FW). Her identity and ‘sense of self’ was strengthened through this group (Geri, FW).

In order to respond to new referrals to the Headin’ Up program the family workers had to make decisions about the timing and ending of a service to a client family. This process involved reassuring families they could manage, the family workers reflecting on their contribution to the changes families had made, and families sometimes feeling a sense of loss. One family worker, Ruth, was leaving the agency and was closing the files of her client families. When the families heard about this, some expressed a ‘sense of loss’, leading her to reflect on her role with them: ‘The reactions of the families to the news that I’ll be going is a testament … that I have actually contributed a lot to them’. Ruth had wondered how effective her role with some families had been, but their response to her leaving caused her to think: ‘there has been something of real substance here that we’ve been working on together’ (Ruth, FW).

A gradual process of increasing the length of time between visits, ‘four weekly, six weekly’ enabled Tanya to feel confident that she could end the service to a family she had worked with long-term:

I went there and I thought ‘I’m not really doing anything now, I’m just coming for a chat and a coffee’ [and I said]…. and what this is saying is you’re managing fine, you don’t need me, you’re doing fine, you’ve got all the skills and all the coping mechanisms there to manage, and if you are ever unwell you’ve got my number (Tanya, FW).

**Family worker experiences with other agencies**

At the time of study, the 12 families were involved with a number of agencies besides Headin’ Up (as shown in Table 9.1). All were seeing a GP and most were involved with Centrelink, the income support agency. At the start of the study eight and six, respectively, were seeing a public mental health worker or psychologist, though this had decreased to four and three respectively towards the end of the study. Many were engaged with services relating to their
child’s behaviour or management (five were seeing a school counsellor at the start and four at the end of the study).

Some might argue that this indicated a need for interagency cooperation and service coordination so workers from different agencies might understand one another’s roles and responsibilities. Family workers had both positive and negative experiences of other agencies. There was evidence of some collaboration, but they struggled with other agencies’ general lack of regard for families and the impact of mental illness, as well as for the family workers’ role.
Table 9.1: Involvement with support practitioners and agencies

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of Families</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Interview 1</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>12</td>
</tr>
<tr>
<td>Centrelink (income support agency)</td>
<td>10</td>
</tr>
<tr>
<td>Public adult mental health</td>
<td>8</td>
</tr>
<tr>
<td>Psychologist</td>
<td>6</td>
</tr>
<tr>
<td>School Counsellor</td>
<td>5</td>
</tr>
<tr>
<td>Department of Community Services (State child protection authority)</td>
<td>4</td>
</tr>
<tr>
<td>Public child and adolescent mental health team</td>
<td>3</td>
</tr>
<tr>
<td>Child and family health nurse (infants)</td>
<td>2</td>
</tr>
<tr>
<td>Community health</td>
<td>2</td>
</tr>
<tr>
<td>Salvation Army</td>
<td>1</td>
</tr>
<tr>
<td>Brighter Futures (parenting support)</td>
<td>1</td>
</tr>
<tr>
<td>Northern Settlement Services (support for immigrants and refugees)</td>
<td>1</td>
</tr>
<tr>
<td>Samaritans (nongovernment welfare)</td>
<td>1</td>
</tr>
<tr>
<td>Child and family health service (paediatric service)</td>
<td>1</td>
</tr>
<tr>
<td>Reconnect (relationship support for young people with their families)</td>
<td>1</td>
</tr>
</tbody>
</table>

The family workers’ experience at case conferences had made them aware of other workers’ differing attitudes towards these parents. Melanie said it was great when everyone was ‘on the same page’ to set goals for the family and arrange the services needed to achieve those goals. There were also experiences of case meetings:

Where there has been no consideration whatsoever for the family, they are expected to do these things [meet criteria] but not given any help from the other agencies to do
them, just expected to go out and do them and then meet the criteria [of different agencies] ... We work with the family to try and get everyone to work together, and to try and help the parents manage whatever behaviours are happening (Melanie, FW).

Sam continued:

And some of them approach you with huge expectations of the families. Some of the attitudes they carry… I don’t think they have any idea of the impact that they’re having on families’ lives, and the hoops they want these people to jump through, which is near impossible for some … Secrecy can go on, and having case meetings and not involving all the services and not tell the family about it, or springing that on them at the last minute, and then having a meeting before the family gets there and then you all go out a back door and then come back around through the front door as if you’re only just arriving. I mean that’s just wrong I think (Sam, FW).

Melanie was involved in such a meeting. She arrived with the family when ‘everyone else was there’ and, during the meeting:

A lot of what the family was trying to get over to the rest of the people [at the meeting] was pretty much dismissed. …We then asked the question: in all of this what consideration was taken into account for the fact that the child is Aboriginal and, basically, were told ‘none, and that it made no difference’ (Melanie, FW).

Melanie said that workers from two of the other agencies informed the family of requirements they were to fulfil, and workers from the third agency said to the mother (who had borderline personality disorder):

‘Well as far as we’re concerned borderlines don’t get better so your child will be in care until they’re 18 years of age’. So in reality all this stuff [said] in this meeting really pulled the client down ... and emotionally, socially, like drained them of absolutely everything … this person was expected to be able to cope with a newborn baby … and trying to cope with the notion that they’re never going to get one child back (Melanie, FW).
Melanie felt that workers in other services did not understand schizophrenia or borderline personality disorder:

Other services can be very ignorant about what is involved with those diagnoses, and the community can be as well … if there’s a diagnosis of schizophrenia some people can think, oh well schizophrenia, they’re going to let loose and I’m going to get hurt by them … but there are professionals … that have got no idea what these things mean as well. …. I’m working with another agency… that has stated that borderlines do not get better, which is just totally wrong. They may never fully recover … but management wise they can get better … this other agency doesn’t seem to think that … they could be an effective parent, that they could be an effective community member (Melanie, FW).

Tanya described a different experience, where the child protection authority, the Department of Community Services (DOCS):

Bent over backwards to help [a] mum get their child back, and so hopefully there’ll be restoration … I think having our service in there as well, and helping mum like around the depression and things like that has been really beneficial, and being able to go out to the home … to show her how to maintain a home [helped the mother to shift from] being quite depressed to taking the initiative … and asking for help (Tanya, FW).

Natalie (FW) described the ‘clash’ she had experienced between her approach in working with a mother who had been diagnosed with borderline personality disorder and that of a mental health worker:

I’ve been working with a client that has been diagnosed with borderline personality disorder, and I’ve been working with her for quite a while, and she has a mental health worker … she knows she’s been diagnosed with this disorder and, I guess, I’m trying to broaden her perspective of that diagnosis and look at the strengths within it, but then I feel like sometimes, the other worker just puts her into that category and that is really a limiting kind of description of her identity, and sometimes I feel like that clashes
because I’m trying not to kind of buy into that … so, for me, that’s really hard at times (Natalie, FW).

Family workers cited several examples of other workers’ lack of understanding about, and respect for, their role and experience as family support workers. For example, when making a referral to Headin’ Up, some workers ‘think we are going to do work … like clean someone’s house … or get them to do … better and turn their kids into beautiful … well behaved little angels’ (Sam, FW). At a case meeting Jenny said she had been told by a psychologist ‘leave it, leave it, we’re the experts, leave it to us’ (Jenny, FW).

Two family workers also felt patronised by personal comments relating to their ethnicity, or age. One of the Aboriginal family workers had experienced being talked down to, and she felt this was because of her ethnicity, saying that the other workers ‘seem to have this attitude that they know better … than you … and you’ve got to work with that attitude from that other agency … they think they’re superior’ (Melanie, FW). Ageist attitudes of other professionals may also be experienced: ‘I think if you’re a young person working in this field there can be ageist [attitudes]’ (Natalie, FW). Natalie was a younger member of the Headin’ Up team.

Factors facilitating access to support

The factors facilitating, or impeding access to support were influenced by individual factors, by service related factors, and by systems related factors.

‘Getting the help sometimes is just as hard as not getting it’

Responses of family members and family workers showed that characteristics of parents themselves, their relationships with others, cultural respect and sensitivity, and the professional practices of the family workers, were enabling factors. Parents also identified strategies that they thought would help make information about other services more accessible to families.
Parents’ confidence and assertiveness

Rebecca was confident and assertive in seeking services. She stated that she ‘knew what they [services] did, and I went out and did it all myself … I did it all off my own back. The information’s out there’ (Rebecca – interview 1). Rebecca believed that the state mandatory child protection authority was available to help families, and she asked for help from this service when she needed to. Rebecca’s approach to the child protection authority as a source of support was in contrast to many parents who have a mental illness, who worry that involvement will lead to their children being taken from them.

Frances’s assertiveness contributed to her being accepted for a personal skills program included in the Headin’ Up initiative. Frances read about the program in an agency newsletter and, following her enquiry, was advised she was not eligible. Self-advocacy gained her entry to the program, with positive outcomes for her: ‘I loved that support, that meeting every week … identifying with these other women … around kids and difficulties … and then improving yourself and just getting on with life’ (Frances – interview 2).

Mark, a family worker, reflected on his perceptions of parent’s assertiveness:

I learnt a lot from the families who have been quite assertive about looking at options and some of us actually shaping together what’s needed and some parents are very keen to discover what’s around and will look up on the internet and will ring multiple agencies and find out themselves, so it becomes a conversation about what’s been discovered sometimes (Mark, FW).

Longstanding experience of the parent’s mental illness in another family led them to being ‘pretty accustomed to finding what we need’ (Peter).

Relationships with others

Relationships with professionals and partners enabled help seeking and motivated some mothers. Diane ‘was brought up around DOCS (state child protection authority) … [and thought] ‘I was going to get judged about my parenting’. Diane’s relationship with her General Practitioner was pivotal in her wanting to work on her health such as giving up cigarettes and
drugs, with Diane trusting the GP, and ‘she made me feel comfortable. She genuinely cared about me and J and our wellbeing’ (Diane – interview 1). The GP had referred Diane to the Headin’ Up program, and the support of her GP, a social worker, and then the Headin’ Up family worker had been ‘life changing’ for Diane. She had been anxious that in seeking help she ‘might lose everything’ but realised the workers involved were there to support her (Diane – interview 1).

Jane had enjoyed a good relationship with her GP, and said she would encourage families to initially seek out their GP, or a counsellor, to gain referrals to parenting and family support programs. Jane said she had been affected by depressive episodes for 20 years and believed she had gained in confidence in help seeking since having a child, having learnt from experience that services exist which may be helpful. Jane thought it was important that practitioners were up to date about services available to families (Jane – interview 1).

Liana’s relationship with her partner helped to motivate her. With her previous partner Liana ‘had no confidence in myself to want to help myself and get the help’, but now with a new partner, father of her youngest child, Liana wanted ‘to be a better person, so that makes it easier for me to reach out and get all these (phone) numbers and resources’ (Liana – interview 1).

Culturally sensitive activities – ‘good medicine’

An enabling factor specific to Aboriginal families was the use of the traditional creative activity of weaving baskets which enabled Aboriginal women and parents to come together: ‘It’s a way of engaging with the community without it being in your face … we talk about issues … in a way that is not threatening’ (Tanya, FW). The weaving is a metaphor for the ‘yarning’, or talking, that takes place in traditional contexts, and the Aboriginal mental health family workers may identify topics to follow up with a family after the group.

Aboriginal Elders from northern Australia have attended the group, which has been ‘really beneficial’ for the women, with the Elders affirming that sitting together to ‘yarn and laugh’ was ‘good medicine’ (Tanya, FW). Some of the women participating in the group were removed as children, so while ‘knowing they’re black … they haven’t grown up black … in
the [Aboriginal] community [and are] wanting to identify but [are] very unsure about their identity.’ Attending the group has enabled them to ‘claim their identity and feel safe … and [to meet] other Aboriginal people’ (Tanya). The presence on the Headin’ Up team of two Aboriginal mental health workers facilitated the culturally appropriate activities, and the attendance of Elders enhanced the experiences of the group participants.

While parents and carers appreciated the support received from Headin’ Up and other services, they had ideas about how other agencies could make their services more widely known and accessible to families such as theirs. Frances thought that information exchange should occur, such as agencies placing their information pamphlets in churches, financial counselling agencies, and neighbourhood centres. She also thought that family support agencies should emphasise the supportive nature of their services, making it explicit that they do not exist to take children from their parents. Tessa thought that it would be helpful for families who do not have English as their first language to have the information leaflets that are provided in waiting areas explained to them.

**Barriers and setbacks to seeking and receiving support**

The barriers and setbacks which arose for families in seeking and receiving support included attitudinal issues and service provision issues. The stigma of having a mental illness was referred to earlier and, in this context, emerged as a barrier for mothers who were concerned about being judged as parents, and worrying that their children would be taken from them. Parents also experienced service related difficulties such as workers leaving, being told by a mental health service when acutely unwell ‘come back Monday’, and not receiving treatment effective for their particular diagnosis. Barriers also existed for groups with particular needs, such as parents needing respite care for their children, Aboriginal family needs for spiritual and cultural awareness by services, and parents having a first language other than English.

**Worry about being judged as a parent**

A significant barrier identified by families was the ‘huge stigma that if you need this sort of help then you’re bad and that, you know, you’d be judged, and that the kids could be taken
away’ (Frances – interview 1). The fear of child protection involvement was realised for Frances. She had not asked for help or support:

    I suppose I was frightened to ask for help. I [had not] envisaged a mental illness. I just thought that I was a really bad mum … so I didn’t say anything to anyone … I was scared that my children would be taken off me (Frances – interview 1).

    Following arguments between Frances and her daughter ‘the thing I feared [being reported to the child protection authority] happened to me, you know, it’s like the very thing I fear, happened’ (Frances). Frances was particularly concerned that the worker (from another agency), who had made the notification to the child protection authority, had not discussed her concerns with her [Frances] before proceeding.

    Concern about being judged was also expressed by Liana and Diane. Liana believed that people were afraid to get help because ‘of the thought of being hospitalised and the judgement … from others’. Liana included her extended family among those who judged her, and had experienced their lack of understanding as ‘really, really difficult for me, really difficult’ (Liana – interview 1).

    Diane had rejected suggestions of help, feeling ‘overwhelmed with it at first because I thought they were judging the way I am with my son … but I’m realising that’s all a bit of anxiety, too, thinking that I am judged all the time’ (Diane – interview 1). She said that her childhood experiences of mandatory child protection authorities led to her expectation of being judged as an ‘inadequate’ parent. She was concerned that if she were honest with workers about her son’s exposure to family violence, she might ‘lose everything’. Diane believed that having been subjected to domestic violence had made it harder for her to ask for help ‘because I was controlled’ [by my partner] (Diane – interview 1), leaving her with little sense of autonomy and independence.

    Rebecca thought the negative portrayal of mental illness on television would discourage people from seeking help (Rebecca – interview 2), although Rebecca herself was confident in seeking out and asking for help.
A barrier to seeking help noted by family workers was the negative perceptions some of the mothers had about their need to ask for help, and their assumptions about workers’ expectations of them and their parenting. The ongoing nature of some mental health issues may mean that a parent needs continuing services, but the parent’s anxiety about how her parenting will be judged may discourage the parent from seeking help: a parent who felt she was always asking for help ‘feels embarrassed and so then she just doesn’t [ask for help] and things get worse’ (Tanya, FW). Some mothers had perceptions about worker’s expectations of them to be normal which imposed ‘huge pressure’ to ‘appear well’ to get the children to school, to meet the perceived ‘expectation to be normal and functioning’ with parents being afraid ‘I might lose my children if I’m seen to be not managing’ (Tanya), so they do not seek supportive services, as they think this may invite scrutiny of them as parents.

**Inflexible approaches to respite care for children**

One family service that can be supportive to parents is respite care for their children, as it gives parents a break from parenting responsibilities, and children have the opportunity to become familiar with a different family. The topic of respite care highlighted several limiting aspects of service provision: judgemental attitudes about the need for this care, and a lack of responsiveness and flexibility of these services to parents with a mental illness. Respite care for children can support a family in crisis, or may be available on a regular basis as a preventive measure. Despite this, Headin’ Up family workers described differing attitudes of other workers towards respite care. One agency believed that if a parent needed respite for ‘more than a certain number of times a year, that proves they’re [the parent] not able to parent effectively, which is grounds for removing the children’ (Jenny, FW). In one service context parents were allowed ‘two blocks of three months’ of respite care (Jenny). Jenny said the client she referred to did not need ‘a three-month block of respite’, she just needed respite when she was very unwell. The effect of this arrangement was that if the client became acutely mentally unwell between one of these 2 x 3 month blocks of respite care, and asked for more respite care, she risked her children being taken by child protection authorities:
It’s like damned if you do but damned if you don’t. So if you do ask for the help too often … then you’re persecuted. If you don’t ask for the help and you get to a crisis situation and are really not handling it, then you still get persecuted (Melanie, FW).

However, the needs of one family had been acknowledged by the child protection authority, with respite care being planned more flexibly. Even this did not allay the mother’s anxiety, as she stated to the family worker ‘I can’t ask for that until … towards the end of the year or early next year or … they’ll take my kids away’ (Melanie, FW).

Jenny observed that the most helpful response for families needing respite care is that it is available when the care is needed, including in a crisis. Planning for children to stay with the same respite care family on each occasion is preferable, as it can be traumatic for a child separated from her parent to go to a respite care family she does not know (Jenny, FW).

**Setbacks to receiving support, and service provision issues**

The families were involved with an average of just over 5 services each at the time of the first interview, and 4 at the second interview, in addition to Headin’ Up, so it was possible they would experience limitations and setbacks related to service provision.

Parents and carers and Headin’ Up family workers identified limitations concerning some aspects of services provided to the families. In some cases families experienced several changes of worker during the time they were involved with an agency, such as the child protection authority, or the mental health service.

Melanie described one family as being ‘onto their third [child protection] worker’ in two years. (Melanie, FW). While the general expectations of the family were the same in each case, each worker wanted ‘the same thing done but in a different way’ (Melanie).

Claire, a foster carer, had also experienced several changes in child protection workers. A child had been placed in her care by the child protection service, but she had not received information about supports available to her relating to his care. She had been told the child would be seeing a psychologist, but ‘nothing happened’ as there were several changes of caseworkers, so processing of the relevant applications taken up by one caseworker was not followed through by the next one. This impacted on Claire, since she had been promised
follow-up services for the child, but ‘then caseworkers changed, probably three, maybe four times, and everything gets lost, and that’s it’ (Claire – interview 1).

Changes in mental health staff were also experienced as a setback. A good relationship with a mental health worker ended as ‘they’d have to leave’ … and ‘it happens a lot’ (Liana – interview 1). Liana was understanding of the reasons: ‘They’ve either got to go to a different hospital, or they’re moving out of town, but’, she continued, ‘if it happens enough you just, you think, “alright they’re letting me down, what’s the point”’ (Liana – interview 1).

A change in workers may mean that someone has to tell their story again to the new worker which is difficult when traumatic experiences are re-lived in re-telling a personal history. Liana had ‘terrible experiences as a child that will stay with me for the rest of my life’, and each new professional wants ‘to get a bit of background … and you just think “I can’t do this anymore, I can’t keep telling my story”’ (Liana – interview 1).

Community adult mental health followed a procedure of closing a client’s case ‘when they’re well … sort of, and not re-opened until they’re unwell again’ (Jenny, FW). Again, this could lead to the client having a new worker, and the re-telling of their personal history, and development of a new relationship with another professional.

Routine workplace occurrences such as cancellation of an appointment may stretch the family’s resources, making it difficult to sustain participation with a service; ‘they have one appointment and the next appointment’s cancelled because the worker is off sick… and it gets a little bit too hard … they have to really work hard to pursue that service’ and feel they have too many hoops to jump through (Lesley, FW). The capacity of the Headin’ Up family workers to make home visits referred to earlier contributed to continuity for families in that program.

Anticipation of a service’s response, based on previous experience, may discourage help-seeking, as Helena described:

If you ring mental health and tell them, yes I’m suicidal. I’m going to kill myself, [they respond] ‘well go to the emergency ward’, we don’t want to hear that, you know, you don’t want to be told ‘go to an emergency ward’, you want them to see you and help you through it, you know, you don’t want them to just, you know, be in your life for a
week to check up on you once a week, every day, because as soon as they go after that, nothing changes, you’re still the same. So no-one wants to ring mental health or no-one wants to ring Lifeline, or no-one wants to do any of that, because they don’t get the support that they need. Further, people don’t want to get help because they don’t want to be told ‘no-one’s here at the moment, ring back on Monday’, who wants to ring back on Monday (Helena – interview 1).

Helena’s frustration was compounded when she felt there was a lack of understanding and effective treatment response to her mental illness of borderline personality disorder, with practitioners thinking ‘that giving medication is the way to treat it’ (borderline personality disorder), where medication ‘doesn’t treat what I’ve got. It can help it but it doesn’t treat it’. Helena believed she needed ‘proper psychotherapy’ but did not receive this. In attempts to get help Helena made repeated suicide attempts: ‘I’ve done it many times, being admitted to hospital, and they tell me I’m fine, just so I don’t get admitted, so I get to go home, [they say] I’m OK, “it was an accident”, it wasn’t an accident. I need to do it [attempt suicide]’ (Helena – interview 1). The lack of effective response to her disorder and treatment needs continued when Helena was referred to a counsellor at a rehabilitation service who admitted she did not know anything about borderline personality disorder, an admission Helena said she respected.

Family Support Newcastle supports families from backgrounds that are diverse linguistically and culturally, including Aboriginal and Torres Strait Islanders (ATSI), with three (25%) of the parents and carers in the study coming from diverse backgrounds.

Two mothers spoke a first language other than English, which was a significant barrier, initially isolating them from services, and potentially supportive networks. They had come from other countries to Australia as adults. Tessa said:

There was a time when I did not speak with anybody because I was afraid of my English, my English was not good enough, and I feel sometimes embarrassed when I’m not saying [things] the right way (Tessa – interview 1).

Tessa said that for a long time she did not use telephone books to find services, but relied on the doctor to give her the contact details for services, nor did she take written material on display stands in government offices because she could not read it. Tessa observed that
when people felt welcomed by a worker who didn’t ‘care [about] the way you speak’ [this enabled them to] ‘feel really safe and comfortable so you could say whatever you feel like’ (Tessa). In the past, Tessa had felt pushed away, being told by a worker ‘I don’t understand what you are saying’, leaving her feeling rejected and removed from the queue so others waiting for service could be assisted (Tessa).

When approaching a service Aboriginal families generally need to feel they will receive a culturally sensitive response, however in the Newcastle area this was difficult as ‘there’s just not enough Aboriginal workers on the ground’ (Tanya, FW). Families of Aboriginal background ‘need to see a face that they know and feel safe with … they’re not just going to come in’ [off the street, to the agency] (Tanya). This means that they need to know they will be speaking with someone who understands their cultural context, and that mental ill health is viewed from a spiritual point of view by Aboriginal people. It is important that they can ring a worker who is ‘able to identify with the issues on … a bit deeper level’. The weaving group described above, and occasional ‘community outreach activities’, when time permits, have been attempts to engage with more Aboriginal families (Tanya).

Negotiating with Federal and State government agencies may be necessary for a parent or carer, but also overwhelming, with these entities being autonomous. Chapters 5 and 6 discussed the policy and service context for this study, including summaries of the Federal and State jurisdictions for health policy and family support policy, highlighting the complexity of each system, which is further compounded for a parent or carer seeking services from both.

Families may need to negotiate with two Federal bureaucracies: Centrelink is the source of income support for Australian individuals and families needing this support, and Medicare manages health related matters; State governments financially support carers of children, such as foster carers and grandparents (that is, those who know about and seek access to these supports). The autonomy of the Federal and State jurisdictions was experienced by Alex who felt like ‘I was batted, you know, it was like a tennis match between (State department of community services) and Medicare (Federal), because one’s a State agency and one’s Federal and I ended up after many, many months bursting into tears’ (Alex – interview 2).
On another occasion, in response to frustration and desperation at having to complete certain forms every fortnight for Centrelink ‘for years and years and years’, Alex had called on a member of parliament:

Well I rang her office… and I just spoke to one of the people who work for her and I said ‘I am over this’, and they rang Centrelink and Centrelink rang me back, and you think of the mouse that roared, you know, it’s wonderful (Alex – interview 1).

Alex’s knowledge and understanding of community leaders she could access, and awareness that this approach may be effective for her, may not be readily available to others.

Conclusion

This chapter presented the findings on social support showing that families were the first and most valued means of support for some participants, and where outside support was needed, GPs were the next port of call. What was appreciated in the Headin’ Up program was the flexible service delivery, and especially the home visits. Overall, the participants were positive about the Headin’ Up support they had received, though most were involved with multiple agencies at the time of the study. Most were concerned about personal issues and valued the direct information and support received, especially about how they were coping with their mental illness and the management of their children. Further discussion of these findings continues in Chapter 11. The following chapter presents the study’s quantitative findings as mentioned at the outset.
Chapter 10

Findings: Family functioning and service involvement

Alongside the interviews, standardised self-report measures were introduced to gain an understanding of the overall functioning of these families living with mental illness. The first-person accounts described in Chapters 8 and 9 provided an in-depth understanding into the episodic nature of mental illness and how life was a continual struggle for this group of families. They further alerted the researcher to the minimal nature of the support received and the mothers’ and carers’ personal concerns and issues. Provision of support to families responds to their day-to-day needs, but does not address structural issues affecting their lives. As outlined in the study’s methodology in Chapter 7, the self-report questionnaires were completed by the primary caregiver (n=12) in each family, that is mothers, grandmothers and foster carer, on their family’s behalf. With the exception of the Family Background Questionnaire, which was completed once, the questionnaires were administered on two occasions, approximately six months apart in most cases. They were as follows:

**Family background, relationships, and coping ability questionnaires**

1. Family Background Questionnaire (FBQ) was completed at the first interview (see Chapter 8, Table 8.2; Appendix VI.1)
2. MacMaster Family Assessment Device General Functioning subscale (FAD-GF) (Table 10.1, 10.2; Appendix VI.2)
3. Family Crisis Oriented Personal Scales (F-COPES) (Table 10.3-10.7; Appendix VI.3)

**Service-related questionnaires**

4. Service Coordination (SC) (Table 10.8; Appendix VI.4)
5. Family Participation in Planning (FPP) (Table 10.9; Appendix VI.5)
6. Services your family may have been involved with (Appendix VI.6), discussed in Chapter 9.
The two sets of questionnaires completed by each parent-carer were examined, coded, entered into Excel, and imported into SPSS Version 21. Little’s (1988) MCAR (Missing Completely at Random) test was applied to various scales to test whether values were completely missing at random. If values were missing at random, the imputations were calculated and results compared. Reversals for the negatively worded questions were created if indicated, and paired T tests or linear mixed models were used to calculate differences in mean values for all scales and subscales over the two interview times. No statistically significant differences between Interview 1 and 2 were found for any of the scales or subscales. Findings for family relationships and coping scales are presented first, followed by those for the service-related questionnaires.

Family relationships and coping

Family functioning

The first family relationship and coping measure – FAD-GF (Family Assessment Device-General Functioning) – invited responses relating to emotional expression, communication styles, and problem solving within the family (Table 10.1, Appendix VI.2). Following data entry of responses to the FAD-GF statements, reversals for the negatively worded questions were created.

Table 10.1 shows the number and proportion of participants rating responses of strongly agree or agree to each statement at Interviews 1 and 2. These responses were considered alongside the first-person accounts reported in Chapters 8 and 9, and attest the complexity of family relationships among these families.

Responses were consistent at Interview 1 and 2 for several statements, with 11 (91%) agreeing that individuals were accepted for who they are (statement 4), and that families are able to make decisions on solving problems (statement 10). Eight respondents (66%) agreed on both occasions that family members confided in each other (statement 12). Responses to other statements appear to show increases and decreases in agreement from Interview 1 to 2,
such as 9 (75%) respondents agreeing that family members could turn to each other for support in a crisis at Interview 1, with 11 (91%) agreeing at Interview 2.

**Table 10.1: Respondents who strongly agreed or agreed with FAD-GF statements**

<table>
<thead>
<tr>
<th>Statements</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other</td>
<td>7 (58%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>2. In times of crisis we can turn to each other for support</td>
<td>9 (75%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>3. We cannot talk to each other about sadness we feel</td>
<td>7 (58%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>4. Individuals are accepted for who they are</td>
<td>11 (91%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>5. We avoid discussing our fears and concerns</td>
<td>6 (50%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>6. We can express feelings to each other</td>
<td>8 (66%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>7. There is lots of bad feeling in the family</td>
<td>3 (25%)</td>
<td>2 (16%)</td>
</tr>
<tr>
<td>8. We feel accepted for who we are</td>
<td>10 (83%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>9. Making decisions is a problem for our family</td>
<td>6 (50%)</td>
<td>5 (42%)</td>
</tr>
<tr>
<td>10. We are able to make decisions on how to solve problems</td>
<td>11 (91%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>11. We do not get along well together</td>
<td>2 (16%)</td>
<td>2 (16%)</td>
</tr>
<tr>
<td>12. We confide in each other</td>
<td>8 (66%)</td>
<td>8 (66%)</td>
</tr>
</tbody>
</table>

Table 10.2 shows the scores on the FAD-GF for each family at both interviews. The higher the score, the greater the difficulties in family communication, problem solving, and emotional responsiveness. There was little variation in the scores between the interviews. At

**Table 10.2: Mean family functioning (FAD-GF) scores**

<table>
<thead>
<tr>
<th>Family</th>
<th>Interview 1 FAD-GF Score</th>
<th>Interview 2 FAD-GF Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2.50</td>
<td>2.08</td>
</tr>
<tr>
<td>2</td>
<td>2.33</td>
<td>2.83</td>
</tr>
<tr>
<td>3</td>
<td>*2.18</td>
<td>2.33</td>
</tr>
<tr>
<td>4</td>
<td>2.67</td>
<td>2.17</td>
</tr>
<tr>
<td>5</td>
<td>2.33</td>
<td>2.08</td>
</tr>
<tr>
<td>6</td>
<td>*2.50</td>
<td>2.08</td>
</tr>
<tr>
<td>7</td>
<td>1.64</td>
<td>1.42</td>
</tr>
<tr>
<td>8</td>
<td>1.75</td>
<td>2.08</td>
</tr>
<tr>
<td>9</td>
<td>1.92</td>
<td>1.83</td>
</tr>
<tr>
<td>10</td>
<td>2.92</td>
<td>3.17</td>
</tr>
<tr>
<td>11</td>
<td>1.75</td>
<td>1.75</td>
</tr>
<tr>
<td>12</td>
<td>1.33</td>
<td>2.08</td>
</tr>
</tbody>
</table>

*Scores were divided by 11 for family 3 and family 6 as they each missed 1 item.*

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the time of the first interview, the mean FAD-GF scores for families ranged from 1.33 to 2.92 with 7 (58%) having a mean score of more than 2.0. At the time of the second interview, the mean FAD-GF score for the families ranged from 1.42 to 3.17, with responses for five families appearing to show an increase in FAD-GF score, indicating ongoing difficulties. Responses for six families appeared to show a slight decrease in FAD-GF score at Interview 2, and the score for one family did not change.

**Family’s coping ability**

The second family relationship and coping measure administered was the F-COPES (Family Crisis Oriented Personal Scales (see Appendix VI.3). It measured the family’s coping ability through seeking and receiving support, and reframing problems. F-COPES comprises five sub-scales: social support (Table 10.3), reframe (Table 10.4), mobilise family (Table 10.5), passive appraisal (Table 10.6), and spiritual support (Table 10.7), with a differing number of statements in each subscale. Each F-COPES statement was scored on a 5-point scale from 1 - strongly disagree to 5 - strongly agree, with the exception of the passive appraisal sub-scale in which scores were reversed. Statistical analysis showed no significant difference between Interviews 1 and 2 for any of the five sub-scales.

The nine statements in the social support sub-scale (Table 10.3) could be organised into three groups: relatives, friends, and neighbours. The responses are illustrative of minor variations from Interviews 1 to 2, but mostly bear out the first-person accounts of experiences of support reported in Chapters 8 and 9. Interestingly, though the first-person accounts showed a reliance on family support, these scores indicate a higher level of disclosure to friends and very little support from neighbours, which bears out the findings in Chapter 9 on sources of support.
Table 10.3: Respondents who strongly agreed or agreed with the F-COPES Social Support sub-scale statements

<table>
<thead>
<tr>
<th>When we face problems or difficulties in our family we respond by:</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sharing our difficulties with our relatives</td>
<td>5 (42%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>2. Seeking encouragement and support from friends</td>
<td>7 (58%)</td>
<td>9 (75%)</td>
</tr>
<tr>
<td>3. Seeking advice from relatives</td>
<td>6 (50%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>4. Accepting gifts from neighbours</td>
<td>1 (08%)</td>
<td>2 (16%)</td>
</tr>
<tr>
<td>5. Asking neighbours for assistance</td>
<td>2 (16%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>6. Sharing concerns with close friends</td>
<td>9 (75%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>7. Doing things with relatives</td>
<td>4 (33%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>8. Asking relatives how they feel about problems we face</td>
<td>5 (42%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>9. Sharing problems with neighbours</td>
<td>1 (08%)</td>
<td>3 (25%)</td>
</tr>
</tbody>
</table>

The Reframe sub-scale (Table 10.4) presents eight statements (10-17) which assess a family’s ability to redefine stressful events, and make them more manageable. These results show these families were accustomed to dealing with crises and mostly believed they had the power to solve problems. However, they still had difficulty accepting the challenges life sent their way but mostly remained strong.

Table 10.4: Respondents who strongly agreed or agreed with F-COPES Reframe sub-scale statements

<table>
<thead>
<tr>
<th>When we face problems or difficulties in our family we respond by:</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Facing problems ‘head on’ and trying to get solutions right away</td>
<td>7 (58%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>11. Accepting that difficulties occur unexpectedly</td>
<td>4 (33%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>12. Accepting stressful events as a fact of life</td>
<td>10 (83%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>13. Believing we can handle our problems</td>
<td>6 (50%)</td>
<td>7 (58%)</td>
</tr>
<tr>
<td>14. Showing that we are strong</td>
<td>10 (83%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>15. Knowing we have the power to solve major problems</td>
<td>12 (100%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>16. Seeing the family problem in a more positive way so we don’t become too discouraged</td>
<td>7 (58%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>17. Knowing that we have the strength within our own family to solve our problems</td>
<td>6 (50%)</td>
<td>9 (75%)</td>
</tr>
</tbody>
</table>
The four statements in the Mobilise Family help-seeking sub-scale (Table 10.5, statements 18-21) concerned a family’s attempts to get help when facing problems. In the first-person accounts, GPs were mentioned frequently by most respondents. In these responses, professionals and helping agencies and non-family members seem to be used more often than GPs.

**Table 10.5: Respondents who strongly agreed or agreed with F-COPES Mobilise Family sub-scale statements**

<table>
<thead>
<tr>
<th>When we face problems or difficulties in our family we respond by:</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Seeking information and advice from the family doctor</td>
<td>4 (33%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>19. Seeking professional counselling and help for family difficulties</td>
<td>11 (91%)</td>
<td>9 (75%)</td>
</tr>
<tr>
<td>20. Seeking assistance from community agencies and programs designed to help families in our situation</td>
<td>11 (91%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>21. Seeking information and advice from persons in other families who have faced the same or similar problems</td>
<td>10 (83%)</td>
<td>10 (83%)</td>
</tr>
</tbody>
</table>

The Passive Appraisal problem-solving sub-scale (Table 10.6) concerned the ability of a family to ignore problems and minimise negative reactions. There is a certain fatalism in these responses that no matter what they do they will have difficulties solving problems and luck plays a part in getting them through. Given scores for statements on this sub-scale were reversed, the higher the mean score for a statement, the more the participants disagreed with it. It would seem that at Interview 2 the proportion of participants disagreeing with the statements was most noticeable for statement 25, which could indicate a trend towards increased confidence in the family’s ability to handle problems at the time the scale was administered.
Table 10.6: Respondents who strongly agreed or agreed with F-COPES Passive Appraisal sub-scale statements

<table>
<thead>
<tr>
<th>When we face problems or difficulties in our family we respond by:</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Believing if we wait long enough the problem will go away</td>
<td>6 (50%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>23. Knowing luck plays a big part in how well we are able to solve family problems</td>
<td>8 (66%)</td>
<td>8 (66%)</td>
</tr>
<tr>
<td>24. Watching television</td>
<td>4 (33%)</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>25. Feeling no matter what we do we will have difficulty handling problems</td>
<td>8 (66%)</td>
<td>11 (91%)</td>
</tr>
</tbody>
</table>

The sub-scale Spiritual Support (Table 10.7) comprised four statements concerning the family’s spiritual engagement. As in the first-person accounts, only one participant professed to a religious faith, and spiritual support did not feature to any significant degree in these families’ lives.

Table 10.7: Respondents who strongly agreed or agreed with F-COPES Spiritual Support sub-scale statements

<table>
<thead>
<tr>
<th>When we face problems or difficulties in our family we respond by:</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. Attending services related to my religious or spiritual faith</td>
<td>2 (16%)</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>27. Having faith in a religious or spiritual figure or place</td>
<td>1 (8%)</td>
<td>2 (16%)</td>
</tr>
<tr>
<td>28. Participating in activities related to my religious/spiritual faith</td>
<td>0</td>
<td>1 (8%)</td>
</tr>
<tr>
<td>29. Seeking advice from a minister of religion or spiritual leader</td>
<td>2 (16%)</td>
<td>3 (25%)</td>
</tr>
</tbody>
</table>

The F-COPES sub-scale mean scores for Interviews 1 and 2 have been compared with norms for two groups presented by McCubbin et al. (1996) (Table 10.8). They presented scores for African-American and Caucasian families with adolescent boys, with the scores for Caucasian families only presented.
Table 10.8: F-COPES sub-scales mean scores compared with scale norms

<table>
<thead>
<tr>
<th>F-COPES sub-scales</th>
<th>Interview 1 (n=12) Mean</th>
<th>Interview 2 (n=12) Mean</th>
<th>Norms*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sole parent families (n=32)</td>
</tr>
<tr>
<td>Social Support</td>
<td>25.548</td>
<td>26.667</td>
<td>28.41</td>
</tr>
<tr>
<td>Reframe</td>
<td>29.826</td>
<td>30.374</td>
<td>28.43</td>
</tr>
<tr>
<td>Mobilise Family</td>
<td>15.870</td>
<td>16.000</td>
<td>13.79</td>
</tr>
<tr>
<td>Spirituality</td>
<td>8.50</td>
<td>10.25</td>
<td>12.86</td>
</tr>
</tbody>
</table>

*McCubbin et al. (1996)

The most noticeable differences in mean scores between the study group and the sole parent and nuclear parent families (McCubbin et al., 1996) were in responses to Spirituality statements, where study group families appeared to rely less on spiritual leaders and institutions, and the Passive Appraisal statements where they appeared to be less inclined to respond passively to problems.

Service involvement

Service coordination

The Service Coordination Scale (Table 10.9, Appendix VI.4) measured the extent to which the participants – mothers, two grandmothers, and a foster carer caring for their children, grandchildren, and foster child respectively – had been involved in determining the support they needed and the extent to which the family support workers and other service providers had worked together with them (statement 1). They were required to indicate their level of agreement with the nine items on the scale rated from 1 to 5, not true to very true, with scores for statements 3, 4, 7, and 9 reversed.
Table 10.9: Respondents who responded very true or mostly true to the Service Coordination scale statements

<table>
<thead>
<tr>
<th>Statements</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Service providers have worked together for me and my family</td>
<td>10 (83%)</td>
<td>9 (75%)</td>
</tr>
<tr>
<td>2. The workers from the different agencies seem to agree on a single plan</td>
<td>4 (33%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>3. The information received from various agencies/workers is contradictory</td>
<td>0</td>
<td>4 (33%)</td>
</tr>
<tr>
<td>4. The staff from the different agencies disagree on what care my child</td>
<td>1 (8%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>5. The staff from the different agencies have given me good information about my child’s care/my care</td>
<td>9 (75%)</td>
<td>7 (58%)</td>
</tr>
<tr>
<td>6. When we have been referred to new providers/agencies the staff are aware of my child’s situation/my situation</td>
<td>7 (58%)</td>
<td>5 (41%)</td>
</tr>
<tr>
<td>7. When a new worker/service provider has become involved he or she is unaware of my child’s situation/my situation</td>
<td>4 (33%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>8. Staff members from one agency have helped me get services from other providers</td>
<td>7 (58%)</td>
<td>5 (41%)</td>
</tr>
<tr>
<td>9. There is no cooperation among the agencies/workers giving services to my child/to me</td>
<td>1 (8%)</td>
<td>1 (8%)</td>
</tr>
</tbody>
</table>

The statements reflected the degree to which other services worked together in a consistent manner (e.g., statement 2), and provided consistent information (e.g., statement 3). While no direct association can be made, basically this scale confirms concerns relating to the complexity of the service bureaucracy with which these low-income families have to deal. Yet, ironically, only one participant agreed there was no cooperation between services (statement 9) which seems to indicate some inconsistency in first-person accounts and the response to this item.

Family Participation in Planning (FPP)

The FPP questionnaire, as its name implies, measured the degree to which the mothers, grandparents and foster carer had been involved in service planning (Table 10.10, Appendix VI.5). The Family Participation in Planning Scale contained six items, with responses to each one rated from 1-4, no involvement to high involvement, i.e., they had participated in planning
to the extent that the family support workers and other practitioners worked together with them. For the most part, a collaborative approach is evident from these responses.

Table 10.10: Respondents who felt involved (rating 3 or 4) with the Family Participation in Planning scale statements

<table>
<thead>
<tr>
<th>Statements</th>
<th>Interview 1 No. (%)</th>
<th>Interview 2 No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your involvement in planning services your family needs (‘high’ to ‘no involvement’)</td>
<td>7 (58%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>2. How much do you think your ideas are valued in planning services for your family (‘highly valued’ to ‘not valued’)</td>
<td>8 (66%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>3. How would you rate your level of agreement in the plans that are made for your family (‘high’ to ‘no agreement’)</td>
<td>11 (91%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td>4. How would you rate your role in planning for services your family is to receive (‘significant role’ to ‘no role’)</td>
<td>11 (91%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>5. How much would you say the needs of your whole family are considered when services are being planned (‘very much’ to ‘not considered’)</td>
<td>7 (58%)</td>
<td>11 (91%)</td>
</tr>
<tr>
<td>6. How would you rate the level of influence you are able to have in the planning process (‘high’ to ‘no influence’)</td>
<td>10 (83%)</td>
<td>10 (83%)</td>
</tr>
</tbody>
</table>

The statistical data on family functioning, relationships, and coping, and family involvement with services, support what was learnt from the first-person accounts. The aim was not to assess change over a relatively short period of time but to better understand the daily struggles of a group of Australian families. The families in this study were among the most vulnerable, all were on low incomes, most had to deal with Centrelink, and several were involved with the child protection authorities, while others were afraid of this involvement. Many turned to their GPs but most turned to family and friends – people known to them whom they trusted. Thus those who turned to the Headin’ Up program talked of being hesitant at first, learning to trust their family support worker, and realising they were on their side.
Conclusion

This chapter has presented the quantitative data that supports the first-person accounts given in Chapters 8 and 9. Collectively these findings reveal that the families in the study had low incomes compared with Australian averages, and 17 (45%) of the total of 38 children and adults in the 12 families had a mental illness. The first-person accounts attested to the difficulties with family life, relationships, and the service system, though also showed how the strengths-based approach used by the family support workers had instilled some belief in the participants’ capacity to manage their day-to-day lives, especially their children and their mental illness. Insights of all participants, including family support workers, emphasised the importance of a relational perspective when working to support children and families living with a family member with mental illness. It is important to understand the lived experience of people living with mental illness and this study has yielded rich data on this and on their experiences of family support to help them deal with personal issues. In the following chapter, these findings are discussed in relation to prior research and the theoretical framework informing the study.
Chapter 11

Discussion

This exploratory study aimed to give voice to children and families living with a family member with mental illness and understand their experiences of support and the context in which it was given and received. In pursuit of this aim, the study brought together two fields of service provision: mental health within the health sector and family support within the social services sector. A case study approach was used, with the group of families constituting the case under study within the context of policies and programs relating to the twin concerns of mental illness and family support. Family wellbeing is concomitant with support and this aspect of family life was also the subject of study.

The study was informed by four interrelated bodies of theory and research, which contributed to understanding the experiences of the children and families: ecosystems theory, and theory and research relating to stigma, recognition, and social support (presented in Chapters 3 and 4). Ecosystems theory offered a framework to study the social ecology of families (Jack, 2000). Families who were the focus of this study were involved in different systems that influenced their physical and mental health, and the parenting and the raising of children. Influences within the family, the micro-system, and from external sources led to the need for support services from the Family Support Newcastle Headin’ Up program, and other services. The relationships between agencies, the meso-system, described by the family workers and referred to by parents, showed cooperation, and also showed lack of understanding of family worker roles by other workers. Families were affected by the actions of the funding body, a component of the exosystem, with the periodic uncertainty of funding for the Headin’ Up program leading to staff employed on contracts leaving to find other positions, and subsequently funding for the program ceasing. The funding body also determined the focus for implementation of the Headin’ Up program, which followed mental health policy requirements of promotion and early intervention, initially with a family focus, though this was later changed by the funding body to a focus on children and young people.
The ecosystems framework contributes to understanding the influence of attitudes and values, the macrosystem, which, in the context of this study, included the stigma associated with mental illness that influenced parents’ perceptions of themselves as parents and led them to worry that their children would be taken from them by the welfare authorities. Finally, the ecosystems framework illustrated the links and interrelationships between health and wellbeing and inequalities of income and opportunity in education, housing, and employment, with the families in this study having an income that was two-thirds of the average annual income for all households in Australia at the time the study was conducted. The mutual interaction between environmental inequalities, poor health, and disability, and their impact on families, has been shown in many studies (Jack, 2000).

The stigma associated with mental illness has enveloped those affected through the ages (Scull, 2015) and, despite public education campaigns in Australia, and self-identification of creative, intellectual, and sporting personalities experiencing mental illness, parents with dependent children continued to worry about how their parenting ability would be judged by others. Children, adults, community members, and health professionals with negative attitudes towards people with mental illness led to pessimism about recovery, as shown in the findings of this study. Negative attitudes were identified as a ‘huge’ barrier, discouraged help-seeking, and discouraged children from discussing their home situation outside the family.

Interrelated with stigma in the context of this study was the theory of recognition, a theory of value in which mutual respect and understanding for the dignity of others conferred meaningful recognition and dignity on the self (Yar, 2003) through three forms of recognition in: primary relationships; individual rights; and social solidarity (Honneth, 1995). The stigma of mental illness denied recognition, which led to the internalisation of negative self-images (Morrison, 2010). Parents’ struggle for recognition was evidenced by their aspirations for self-realisation and healthy relationships (Cortis, 2007a). They strove to develop relationships with neighbours, confidence through group participation, and authenticity, despite their perceptions of being judged.

Social support was a protective factor in health and mental health, with access influenced at each level of the ecological system: support available within the family and the
community, with influences on access including program funding and policy influences. Access to support was also affected by the location of services, inclusion criteria, flexibility in service delivery, cultural sensitivity, including language barriers for non-English-speaking people, and the degree of coordination among services to make referrals to one another and effectively pass on information as required.

The two service provision aspects to this study were mental illness and family support, specifically, the participants’ lived experience of mental illness and family support, the source and nature of the support received, and the factors facilitating or impeding access to support. The study explored the experiences of a group of families receiving services from a nongovernment family support service, within the context of broader mental health and family support programs and policies. Interviews were conducted with family members and agency mental health family workers. The main findings emerging from this study were:

1. Families called on families and friends for support
2. Parent and carer relationships with family workers were based on mutual respect and trust
3. Parents and children were supported by family workers’ home visits
4. Parents and carers valued being involved in service planning
5. Inadequate coordination among agencies may lead to confusion for families
6. Access to support for families was facilitated by parents and carers, and practitioners
7. Families experienced barriers to support at the family, service, and organisational levels
8. Adults and children need to understand the mental illness experienced by themselves or by a family member
9. Families experienced stigma, with their responses reflecting individual choices and assertiveness
Families called on families and friends for support

Studies of families where a family member experienced mental illness focused, generally, on issues and needs of parents caring for adult, or young adult family members (as discussed in Chapter 2). This study of children and families living with a family member experiencing mental illness focused explicitly on primary carers, including parents (mothers), grandparents (grandmothers), and maternal foster carers. Some of these carers had a mental illness, some were caring for a child with mental illness, and, in some families, both an adult and a child had a mental illness.

The main findings relating to social support were discussed in Chapter 9. Most participants turned to their families first, showing the importance of familial connections. Where there were strong ties at the individual-family level, these acted as a buffer against the stress related to living with mental illness. Some participants had these strong ties, for others the need or desire for strong ties was thwarted by physical or emotional distance. When it came to facing problems, friends were more likely to be called on for support than family members, shown in participant responses to the F-COPES Social Support sub-scale (Table 10.3, Chapter 10).

These findings pointed to the need to understand relationships within families, the availability of practical and emotional support, and whether or not it was wanted or requested. In practice it may be desirable to involve family members, and mental health policies have given political impetus to their role, but understanding the complexity of relationships within each family, as shown herein, can only arise from direct engagement with them (Bland & Foster, 2012).

In keeping with the ecosystems framework, beyond the support of family members, families were also involved with multiple agencies from whom they received variable support (see Table 11.1). They valued this involvement, and especially appreciated home visits, while the relationship between the participants and family workers influenced their perceptions of the quality of support received.
Table 11.1: Findings in the context of ecosystems, and theories of recognition and stigma

<table>
<thead>
<tr>
<th>Ecosystems</th>
<th>Description</th>
<th>Relation to the families studied</th>
<th>Findings</th>
<th>Theory of stigma</th>
<th>Theory of recognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Microsystem</td>
<td>The family unit and immediate environment.</td>
<td>Family living with a family member with mental illness, and degree of available support.</td>
<td>Participants had varied ties to family, and friends. Self-doubts about parenting by mothers.</td>
<td>Impact on self-confidence</td>
<td>Importance of love and friendship in primary relationships, with family and friends called on first when support was needed</td>
</tr>
<tr>
<td>Mesosystem</td>
<td>The interconnections between the structures of the microsystem.</td>
<td>Relationships among agencies with whom the family related.</td>
<td>Lack of understanding about the role of family workers by some practitioners; cooperation occurred between agencies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exosystem</td>
<td>The institutional infrastructure – policies and services, including education, health, welfare, legal, and financial provision.</td>
<td>Development of policy and service activity influencing the lives of families and children.</td>
<td>Families valued the support of family workers and other service providers. Facilitators and barriers to support identified at each eco-system level. Judgements made about recovery, and parenting.</td>
<td>Negative attitudes experienced.</td>
<td>Acknowledgement of rights in relationship with family workers, and focus on family strengths Solidarity gained through participation in groups by some mothers.</td>
</tr>
<tr>
<td>Macrosystem</td>
<td>Cultural values, customs, and laws that influence community attitudes to mental illness. The parallel policy and service context for mental health and family support.</td>
<td>Influence on policy, funding, and service provision to families and children living with mental illness</td>
<td>Increasing role of consumers and carers in the development of mental health policy and services, including a recovery orientation to mental health service provision.</td>
<td>Possible impact on funding for mental health research, and service provision.</td>
<td></td>
</tr>
<tr>
<td>Chronosystem</td>
<td>Relates to individual and family life-cycle changes.</td>
<td>Effects of health and illness on developmental changes for individuals and families.</td>
<td>Changes in relationship dynamics between parents and children as parents became well.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Support was also derived through participation in group activities and this contributed to a sense of belonging and identity, as in Alex’s engagement in a support group for grandparents, and the group that several mothers attended. Family workers noted that a group for Aboriginal mothers attended by Aboriginal elders had affirmed their identity, due to its cultural relevance.

The provision of strong community-based support was pivotal for these families living with mental illness. Hence, the government needs to fund nongovernment, community-based support services doing this valuable work.

The two young people who participated in this study both lived with a parent experiencing mental illness. They received support from family members, especially a parent or sibling. The older participant, Scott, said his friends were reluctant to talk with him about his parent’s mental illness, preferring to do ‘other stuff’, as he described it, and he understood that. This response was similar to findings of a study of young carers which found a lack of understanding among their peers about their lives and family circumstances (Aldridge & Becker, 2003).

The younger participant, Tom, said he would not talk to anyone outside his family about his mother’s illness, but knew that he could talk to the school counsellor. This paralleled findings by Drost et al. (2015) that children of parents with a mental illness drew on professional help for personal problems. Children have stated that, even when friends did not talk with them about difficulties at home, their emotional support was valued (Gladstone et al., 2011). Good relationships with family members and friends helped children and young people feel normal and connected (Drost et al., 2015), as shown in Table 4.1 (Chapter 4).

Parent and carer relationships with family workers were based on mutual respect and trust

Parents and carers experience of the Headin’ Up family workers was positive, with their relationships being supportive, particularly the availability of the family workers to just ‘talk’ to them. For one parent, the family worker had merely by ‘being there’ saved her life. From the family workers’ perspective, home visiting was invaluable as it offered a
relaxed environment in which to support and encourage positive parenting and healthy child development.

Also invaluable was relational trust between parents and carers and the Headin’ Up family workers. Two mothers, Diane and Rebecca, said it took time before they would ‘let in’ the family worker. Trust and flexibility, established over a long period of time, enhanced the family workers’ capacity to continue working with families, despite inevitable disruptions and missed appointments. It encouraged openness to support as with Tessa’s son. Flexibility was essential given the fluctuating symptoms of mental illness. It acknowledged that parents might want to be independent when they felt well, while recognising that support was available should they need it again later on.

**Parents and children were supported by family workers’ home visits**

Home visiting is a well-recognised and predominant strategy in family support, with a long history. A strength of the Headin’ Up program was the capacity of family workers to routinely make home visits as this was the general mode of service delivery. Home visiting made the program accessible to families and enabled the family workers to offer parents reassurance about their children’s individuality and observe family strengths. The workers’ observations informed their advocacy on behalf of families when this was needed.

However, home visits might also be seen as a form of social control, monitoring parenting practices and child wellbeing, as is required of child protection workers. For the most part, the participants in this study saw their meetings with the family worker in the familiar environment of their home as supportive and appreciated the immediacy of the worker’s observations and feedback about their children. It is likely that a number of the study families, for whom traveling to an office with their children would have been stressful, would not have received a service had home visiting had not been possible.

Family workers also saw children, who were relaxed in a familiar setting, during home visits. The involvement of a family worker with Tessa’s son was a positive experience for her, as he had ‘opened up’ to the family worker and, with her encouragement, had participated in a sporting activity. Tessa and her family did not have extended family members in Australia. The family worker was an adult that her son could
trust, as she was not perceived as an authority figure like a parent or teacher. Tessa was very disappointed for her son when the family worker had to end her service to the family, as the relationship had been positive for him. Tessa’s experience illustrated the interrelationship between support for a child and a parent: support for parents contributes to child wellbeing, and support for Tessa’s son was a positive experience for her.

The perceptions and observations of home visiting described by participants is supported by international evidence on what works in parenting support. A review of evidence found it was:

an effective method of delivery in scores of programs … and has been recommended to reduce risks to child health, and risk of abuse and neglect, and also seems promising in terms of reducing parents’ isolation and improving emotional and mental health (Moran, Ghate, & van der Merwe, 2004, p. 121).

Parents and carers valued being involved in planning services

Parents’ and carers’ wanted to be involved, to feel they were collaborating and playing a meaningful role, shown in their interviews and responses to the Participation in Planning questionnaire. This indicated the importance of participating in the process of decision making on support, apart from attending meetings where decisions were made. A worker who took time to ask for and listen to parent and carer views actively engaged them in a relationship, and in the discussion of the changes that were important to them and their children, and in planning the activities and timeframes involved. Thus participants felt their opinions were taken seriously. This process contributed to enhancing confidence and self-belief, and also conveyed the values of partnership and empowerment represented in Honneth’s (1995) recognition schema of self-confidence, self-respect, and self-esteem. These considerations contrasted with the experiences of a group of parents experiencing mental illness in the UK who felt they had little choice in the services they received: the services were not tailored to meet their individual needs (Aldridge & Becker, 2003).

Parents and carers generally appreciated referrals by practitioners to other agencies, though having to describe the history of their illness to a new service provider
again was frustrating. A practical measure to avoid this duplication would be to seek permission from the client to pass their information on. This would reduce possible retraumatisation for some people, such as the experience Liana recounted in this study.

**Inadequate coordination among agencies may lead to confusion for families**

Generally, families with complex needs were involved with a number of services. In this study, at the time of the first interview, one family was involved with eight agencies, three were involved with seven, and others with 6, 5, or 4 agencies respectively (as shown in Table 9.1, Chapter 9). These services represented three tiers of service provision: Federal, State, and nongovernment agencies, that is, the exosystem in the ecosystems framework. Where several agencies were involved in assisting a family, effective coordination ensured a family was not left with unmet needs, or overwhelmed by services they did not want or need. Participants had mixed experiences, with parents and carers tending to agree that services had worked together though information received from agencies was ‘contradictory’, at times. The difference in responses to service planning and coordination pointed to opportunities to involve parents and carers to achieve more satisfactory outcomes: their involvement in planning might limit contradictory and confusing information giving.

A multidisciplinary and multiagency approach for supporting families where a parent has a mental illness has been advocated for two decades (Aldridge & Becker, 2003; Göpfert, Webster & Seeman, 1996, 2004; Reupert, Maybery, Nicholson, Göpfert, & Seeman, 2015). However, the involvement of a number of agencies may not mean that a family receives a family-focused service, and parents and carers may become confused and have difficulty in identifying which worker is coordinating the system of care, as Aldridge and Becker (2003) found. A risk in this arrangement is that children and young people are overlooked, as, despite a number of agencies being involved, the professionals might not be responding to the needs of families (Aldridge & Becker, 2003).

Effective cooperation, coordination, and collaboration among services required mutual respect and understanding for respective training, roles, and responsibilities, so that families and children were well served. In Bronfenbrenner’s (1979) ecosystems
framework, this is the mesosystem. The Headin’ Up family workers’ observations and experiences of attitudes of other workers towards them were presented in Chapter 9. They spoke of an apparent lack of understanding of their role by workers from other agencies. They felt patronised by responses of psychologists from the child protection team. Claiming to be ‘the experts’, they confirmed their view of the professional hierarchy built on length of training, legal registration, and the right to practice (Hudson, 2002). Psychologists (and other health and allied health professionals) were registered by the national health professionals’ regulation agency. The Headin’ Up family workers represented several professional groups and fields of work, which were not subject to statutory regulation, such as social work, counselling, welfare, human services, community development, and Aboriginal healthcare, all with different training requirements. Nevertheless, the family workers, psychologists, and other child protection team members were required to work together to support vulnerable families. Interdisciplinary arrangements influenced by the organisational settings of practitioners bring differing bodies of knowledge and areas of expertise in working with diverse client groups. These differences need to be respected and accommodated so that practitioners might collaborate in the interests of the children and families they serve.

Access to support for families was facilitated by parents and carers and practitioners

Characteristics of parents and carers, their relationships with others, and service-related issues facilitated seeking out and receiving support. Assertiveness in approaching agencies, confidence in making internet searches, and persistence in being accepted into a mother’s group were examples of individual characteristics. The participants’ individual determination and assertiveness resided in their knowledge that child protection could provide services to support families, their ability to request and use those services, when necessary, and their understanding of how they might use their political influence to facilitate communication between bureaucracies, as required. One parent’s lived experience of needing and receiving help for many years had facilitated the seeking of support through the expertise she had gained. For another parent the support of her partner
gave her the confidence to gather telephone numbers and information about resources for herself and her children.

Relationships with others also facilitated access to related services, with trust in the service provider contributing to this, such as Diane’s trust in her GP who, she felt, had her interests at heart, leading to referral to Headin’ Up.

For Aboriginal families the traditional creative activity of weaving baskets enabled participation of women and parents in an informal setting, with attendance by Elders from northern Australia, who affirmed that sitting and ‘yarning’ was ‘good medicine’.

Families experienced barriers to support at the family, service, and organisational levels

Following an ecosystems pathway through barriers and setbacks families experienced in seeking and receiving support, the first might be analysed at the individual or family level. A significant barrier to support identified by participants was the ‘huge stigma’ associated with mental illness, fear of being judged negatively for needing help, and the threat of the ‘kids being taken away’. This was a constant fear for many parents living with mental illness, with the reality being that, on some occasions, children have been removed from their parents by child protection authorities who determined they were unable to protect their children from abuse and neglect. However, the child protection service was also seen in a positive light, as a source of support. For example, Rebecca was assertive about approaching that service, and others.

Seeking help and support was perceived by some as inviting scrutiny which parents wanted to avoid. On the other hand, a timely service may assist a parent so that children are not taken away, which was the experience of a parent described by a family worker: the parent said that if she had known about Headin’ Up maybe her children would not have be taken from her.

Reluctance to seek help may mean that opportunities for early identification of difficulties, and developmental delays in children, may be missed, placing the responsibility on the parent to know that services exist, and to seek them out. Services
that are accessible, responsive and flexible and available in nonstigmatising environments are more likely to be used by families who are vulnerable (Winkworth et al., 2010).

The isolation of families was referred to by some families. It emerged in their descriptions of sources of support, and was also described by family workers. Several factors likely contributed to this, such as caring for young children and living with a mental illness, not having a car, or living where public transport was infrequent. These factors meant families had limited opportunities to develop informal networks, recognised as important sources of support for parents and their children (Winkworth et al., 2010). Over time, the home visits by family workers helped some parents to develop the confidence to venture from the home.

Participants received varied responses when they called on family members for support. While some described the support they received from family members warmly, in a relationship of reciprocity, for others physical and emotional distance excluded or impacted on this source of support. Some participants received tangible support, such as occasional child care, but talking about important, or emotional, issues did not take place as it imposed feelings of guilt (Ketokivi, 2015), which Jane referred to in her efforts to seek support from her mother. The most important way of conveying feelings to someone that they are loved and cared for is with emotional support; unlike practical support, this would be difficult to contrive for someone wanting emotional support.

Participants also described difficulties at the agency, or exosystem level, such as changes in staff which led to having to repeat their story to the new practitioner. This was Liana’s experience; she was frustrated by this, while philosophical about people ‘moving on’. Continuity of services for the foster child in Claire’s care was impeded by case managers leaving, leading to ‘information getting lost’. Lack of flexibility concerning respite care arrangements for a child meant that the mother with mental illness was fearful of asking for this help and support. This preventive strategy gave her brief respite from parenting responsibilities, if she was not afraid to use it. Family workers reported that agencies providing respite care were inflexible and the care was not necessarily provided when the parent needed it most. They provided ‘blocks’ of care that had little relationship to the parent’s fluctuating illness and associated stress.
Families from culturally and linguistically diverse backgrounds might not seek help and support as it was shameful to do so (Winkworth et al., 2010), or agency responses to language and culture were limited by attitudes, or staffing issues. Participants in this study, such as Tessa, wanted help but her first language was not English and she could not confidently read information, or express her need for a service. On one occasion, she felt pushed to the side because a service provider did not understand her. The shortage of Aboriginal workers was seen by the Headin’ Up Aboriginal family workers as limiting services to their people as they preferred to attend a service where their culture and values were understood by staff of similar backgrounds.

A barrier to support at the mesosystem, or interagency, level occurred when service providers from different agencies failed to communicate about a family who was a client of both, as illustrated by Alex’s example. Alex was struggling to arrange and coordinate services from a Commonwealth government entity, and a State government department for her granddaughter, and resorted to ringing the office of her local Member of Parliament. This achieved the outcome she needed, a strategy not available to everyone. Service providers had opportunities to be proactive when meeting with a family, to enquire about their service needs, and to connect them to other services, and facilitate this process (Winkworth et al., 2010).

Other barriers related to the ending of a service to a family, or termination of funding to the agency. Service to a family was concluded as the allocated duration of service, or number of sessions had been provided, with the existence of a waiting list providing pressure on the worker to ‘close’ the case. In some cases, the uncertainty about continuing funding for Headin’ Up meant that some workers on contracts had to close their cases, and finish with the service.

The termination of funding was a ‘barrier’ as the service was no longer available, such as occurred when the funding for Headin’ Up ceased after approximately seven years of operation. Maintenance of funding facilitated continuity of staff which was recognised as important for families in building relationships between them and their family worker. Ongoing, long-term funding also enabled the development and sustaining of relationships among workers in different agencies who carried knowledge and understanding of the local service environment.
Adults and children need to understand the mental illness experienced by themselves, or by a family member

In the 1990s, national campaigns in Australia raised awareness and understanding of mental illness and, alongside these public-education initiatives, empirical research and publications emerged on mental health literacy, that is, the ‘knowledge and beliefs about mental disorders which aid their recognition, management or prevention’ (Jorm, 2000, p. 396). Assessing the level of mental health literacy provided a base from which to conduct further community education about mental illness to reduce stigma and remove barriers to support and treatment, and highlight the importance of early intervention.

Against the backdrop of these ongoing public-education initiatives, the personal accounts of several parents in the present study showed that they did not know they had a mental illness, leaving them to live with negative feelings about themselves and doubts about their parenting abilities. Their accounts revealed that being informed that they had an illness which could be named, and appropriate treatment provided, was a relief in itself, despite concerns surrounding stigmatising labels and diagnoses. One parent, Liana, understood her illness, but described the negative comments made by relatives about her when they compared her with other people living with depression. Liana responded proactively, locating information leaflets about mental illness, which she gave to her relatives. Although her relatives read this information, it was Liana who had taken responsibility to provide it, rather than her relatives taking the initiative to inform themselves. This finding underscored the differences between the formal clinical mental health system, where patients were diagnosed and treated, and the family support system, where family support and other human service workers often worked with undiagnosed mentally ill people, who, due to the barriers already described, did not access formal treatment.

Article 13.1 of the UN Convention on the Rights of the Child (United Nations, 1991b) states that children have the right to seek, receive, and impart information. This Article applies to children and young people with a mental illness, such as the child in foster care in the present study, who had a diagnosed mental disorder. The foster carer, Claire, said she had not been given information about his mental condition; and it was also likely that the child had not been given an explanation in an age-appropriate way.
about his symptoms. Having this information could have helped him to understand why he was unable to participate in activities that involved being among groups of people in public places, which, according to Claire, caused him to feel anxious.

Children and young people of parents with mental illness, and their parents, have for some years asked that they be given information about their parent’s mental illness. Associated with this, is the knowledge that mental health literacy has been found to contribute to resilience in young people of mentally ill parents (Beardslee & Podorefsky, 1988). Misconceptions about their parents’ mental illness could lead to blaming themselves (Cooklin, 2006), or thinking that if they were ‘good’ and did not attract attention at school they could control their parent’s illness (Crowhurst, 1999). When a child has a parent or sibling with mental illness it is important that the child is identified in a way that respects the privacy of child and family, and that parents decide when and how the mental illness of the family member will be discussed, and whether or not they would like a practitioner to be involved.

Families experienced stigma, with their responses reflecting individual choices and assertiveness

The lack of information in families, the community, and among service providers led to people making ill-informed and negative judgments about a person, such as the experiences described by participants, which affected everyone in a family due to the stigma associated with mental illness. The mothers experiencing mental illness in this study had to contend with misunderstanding and misconceptions leading to doubts about their competency as parents and the stigmatisation of the family as a whole. This affected a parent’s willingness to approach services, request help, and obtain treatment as they were afraid of losing custody of their children (Kelly, 1999). The experiences of several parents, and observations of family workers indicated negative attitudes among human service workers and community members due to a lack of awareness and understanding, which led to negative judgements about parents. Hence Tessa stopped going to church because she believed others found the behaviour of her child unacceptable, Rebecca’s neighbours avoided her, and Helena’s sister displayed displeasure when she recovered from her symptoms, and the father of Jane’s child mocked her in front of her son. The
reported negative judgements about parental competency made by welfare professionals added to the anxieties and demands experienced by the parents and carers.

The intertwined roles of living with a mental illness and parenthood necessitated a holistic professional response acknowledging and supporting the parenting role, while coordinating services and facilitating treatments and support (Aldridge & Becker, 2003). The present study showed how mothers with mental illness felt the need to protect their parental role and adopt the façade of a positive self-image, while perceiving themselves as ‘bad’ mothers, and working to restore and maintain their self-respect and dignity. Frances described this façade as ‘not being able to be real’, and feeling different and ‘isolated in society’. Her subsequent participation in a weekly group had given her a feeling of belonging and identity with the other women. Similarly, Liana described her reclaimed identity as a mother through being a client of Headin’ Up, saying that being part of the program had allowed her ‘to be the mother I want to be and that I’m meant to be’. Adopting a façade to hide their illness and self-doubt and protect their parenting role was fueled by popular images of motherhood, which did not include mothers with a mental illness. This gave rise to a hidden authentic self, and a public persona, the former with an emotionally isolating mental disorder and the latter adopting the mantle of ‘normality’ in social interactions with family and friends (Ke tokivi, 2015). Hence Frances strove to be ‘normal’ while feeling judged because of her mental illness and fearing the removal of her children. The thing Frances had feared most, the involvement of the child protection service, had in fact eventuated. Seen through the lens of Honneth’s (1995) theory of recognition, Frances had hidden behind a façade as she lacked a sense of solidarity or experience of qualitative recognition in the community, and, consequently, had not felt esteemed or validated by others. She had found it a struggle to regain her dignity and restore her self-respect in an environment where negative attitudes and values relating to mental illness predominated. Her participation in a support group with mothers in a similar situation gave her a sense of solidarity.

For the families in general, the focus of the family workers on families ‘doing well’ contrasted with the discouraging nature of stigma or misrecognition, and pessimism about the possibility of recovery expressed by some workers in the system. Stigma was a ‘huge’ barrier to seeking the help necessary for recovery, for some in this study, and acted
as a ‘social disability’ – often contributing to at least the same amount of, if not more, stress than the original mental health issue (Rethink/Institute of Psychiatry, 2002). Including families in recovery approaches to mental illness has been seen as crucial by people with lived experience of mental illness, including parents, children, and partners (Trowse, Hawkins, & Clark, 2013). A family-centred approach to recovery, such as that used by Headin’ Up family workers, acknowledges the roles and needs of all family members and aimed to strengthen individual and family resources. It is a core principle in the National Framework for Recovery-oriented Mental Health Services (Australian Health Ministers’ Advisory Council, 2013b).

The possibility of recovery offered hope for participants in this study, despite ongoing pessimism in some quarters and among professionals, especially surrounding borderline personality disorder and schizophrenia. People with these, and bipolar, disorders have reported feeling significantly less hopeful about their future after seeing a professional about their mental illness (Mental Health Council of Australia, 2011). Though mental health professionals might not be optimistic about outcomes for people with long-term mental health problems, they nevertheless have an important role to play in their recovery. The descriptions of their work with client families given by Headin’ Up family workers Natalie and Lesley conveyed their encouraging and optimistic outlook and understanding of the necessity to work at the client’s pace.

An optimistic outlook meant having hope, i.e. positive expectations for recovery, which was important for the mothers in this study, important for themselves, and for their children. It was also important for other adults, such as grandparents, who were raising the children of parents with mental illness, and for carers of children with mental illness. Parents have reported being sustained by their parenting role, with hope providing incentives to recover and remain well (Diaz-Caneja & Johnson, 2004). In her description of her family’s experience when her husband became unwell, Kerry Hawkins (2014) conveyed hope, positive expectations about his recovery, and a firm belief that her children would be healed following the trauma associated with his illness. Maintaining hope in the context of mental illness symptoms and community stigma, though difficult for mental health consumers, is reinforced when mental health workers ‘hold onto hope’ and work within the client’s frame of reference, acknowledge small gains, encourage
them to try new roles or activities, and believe in their abilities (Darlington & Bland, 1999). Such an approach, used by the family workers in Headin’ Up, went some way to encouraging a sense of hopefulness for the parents and carers in this study. Hence family optimism, belief in the possibility of change, and hope for recovery, could be seen in changes in their relationships with others, such as Rebecca approaching her neighbours, Liana taking initiatives to inform others about mental illness, and participation in community activities, such as attending groups arranged by Headin’ Up.

The impact of stigma on children and young people is aptly described by Goffman’s (1963) term ‘courtesy stigma’, which describes the effect of mental illness on a child who has a parent or family member with a mental illness, though it might also apply to the child’s parents and family members where a child has a mental illness. The dilemma for parents about whether or not to speak with their children about their mental illness was shown in the different approaches, and concerns, of parents in the present study. For example, Liana answered her daughter’s questions openly, Frances talked about her mental illness with her son, but advised him not to talk about it with others, and Jane lacked confidence about speaking with her son as his father had made fun of her mental illness to him. These experiences showed the direct and indirect ways children might be affected by the stigma of mental illness, through the impact on their parents, and their parent’s responses. Liana was determined that she was not going to be defined by her mental illness, and was open about her illness with her young daughter, and willing to speak to students at her daughter’s school. This might give her daughter the skills to deflect bullying or mocking by peers if it occurred, and contribute to her daughter feeling she belonged and was not different from other children.

Responses to mental illness within the family, community, and among service providers placed responsibilities on parents about if, and how, they talked with their children about their illness, with associated anxiety about doing so. This was a choice based on the stigma of mental illness, which differed from choices made about discussing other illnesses with children.

The lack of research on stigma related to childhood mental illness has been attributed to the ‘low status of children throughout history’ and the ‘continuing devaluation of mental disorders’ (Hinshaw, 2005, p. 714). Clearly, attitudes towards, and
experiences of stigma by, young people with mental illness need to be better understood (Jorm & Wright, 2008), especially since almost 14% of young Australians aged between four and 17 years scored in the clinical range for a mental disorder, while just 17% of this group used treatment services (Lawrence et al., 2015).

Regarding policy developments to increase understanding and reduce stigma, the 2008 National Mental Health Policy (Australian Health Ministers, 2009) continued the campaign to increase understanding and reduce stigma relating to mental illness that began in the 1990s. The aim to reduce the negative effects of stigma was partially operationalised through the National Mental Health Plan’s goal to improve ‘community and service understanding and attitudes through a sustained and comprehensive national stigma reduction strategy.’ (Australian Health Ministers, 2009, p. 23). A subsequent cross-government plan, or ‘roadmap’ for mental health reform also sought to address attitudes and behaviours towards people with a mental illness and ensure their rights to participate fully in community life (Council of Australian Governments, 2012). This approach moved towards putting the responsibility onto those with negative attitudes and behaviours, rather than those who were stigmatised due to mental illness (Sayce, 1998). The National Review of Mental Health Programmes and Services recommended that evidence, evaluation, and incentives be used to reduce stigma (National Mental Health Commission, 2014, p. 11). The Australian Government responded with renewed efforts to reduce the stigma associated with mental illness as a core, ongoing responsibility (Department of Health, 2015).

In addition to general community-education campaigns, which alone could not change public attitudes (SANE Australia, 2013), schools were obvious settings for the promotion of education and attitudinal change. Australian programs, such as MindMatters for secondary schools and KidsMatter for primary schools, took a whole-of-school approach to promoting mental health and address the reduction of stigma through curriculum materials and resources for teachers. These programs were components of an integrated approach to child mental health promotion and prevention activity in the Australian Government response to the National Review of Mental Health Programmes and Services (Department of Health, 2015). The effectiveness of this integrated approach has yet to be determined.
Primary-level prevention mainly through public education has been the approach of choice in Australian policy, which has occurred alongside massive changes to the way in which supportive services are offered. Most supportive services are funded through the nongovernment service system, and awarded through tenders and contracts on a programmatic basis. Though mental illness represents 13.3% of total health costs, it attracts only seven percent of the total health budget (Rosenberg, 2011); the contribution of stigma associated with mental illness to this funding disparity remains unexplored.

Since 2006, the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has funded nongovernment organisations to deliver a program of family-focused and community-based services to assist families, carers, children and young people with a family member who has mental health issues (titled Mental Health Community Based (MHCB) programs, Council of Australian Governments, 2006). Family Support Newcastle establishing the Headin’ Up program with this funding. In 2012, the focus shifted from support to families where a child or adult had a mental illness, to family-focused interventions to support children and young people who were at risk of, or affected by, mental illness, targeting children up to the age of 18 years, titled Family Mental Health Support Services (Department of Social Services, 2016). In response to the national Mental Health Commission (NMHC) review of mental health programs and services (NMHC, 2014), the Australian Government undertook to improve the delivery of child, and youth, mental health services through better integration with related services, and partnerships at a regional level, which would include the providers of Family Mental Health Support Services (Department of Health, 2015). Yet funding to Family Support Newcastle to provide these services ended in June 2015.

Similarly, in January 2016 the Children of Parents with Mental Illness (COPMI) program, which focused on workforce development and education, was advised by the federal Department of Health that funding would cease after 15 years. This program assertively engaged and collaborated with service users, young people, and family members as having the lived experience of mental illness that contributed to the development of downloadable resources, and to the face-to-face and online training programs provided.
Conclusion

The families who participated in this study shared similarities, and were also diverse in various ways. All families lived with one or more family members with mental illness, all were concerned for the wellbeing of their children, all had a low income, and all showed the differing ways in which family strengths were realized, and they experienced varying degrees of isolation and stigma. The families were diverse in family composition, the age of family members, the level of support they received from their families, and extent of their links with the community.

The mothers who lived with mental illness lived in fear of child protection authorities, and those parents and carers who had children with mental illness were mainly concerned with how to manage their children. ‘Being seen as a good parent’ was important to all the participants, who had to manage the demands of daily parenting responsibilities, negative social attitudes, and their own symptoms in most cases, often without close family support. Several mothers experienced difficulties in managing these complex demands. They described relationship strains, stigma, isolation, and less-than-helpful responses from professionals. Family workers found parents were socially isolated, with few opportunities to talk about the achievements of their children, and the challenges of parenting, with other mothers. Prior studies found similar tensions for parents with a mental illness caring for young children (Ackerson, 2003; Bassett et al., 1999; Cowling, 1996; Diaz-Caneja & Johnson, 2004; Nicholson et al., 1998).

Despite the difficulties to be managed by the families, it is evident from the accounts of parents, carers and family workers that they had a sense of agency, were committed to meeting the needs of their families, and were engaged with others to achieve this, including family members, friends, family workers, practitioners, and in group settings.

This chapter discussed the main findings of this study. The concluding chapter examines the implications of these findings and makes suggestions for further research and mental health policy and service provision.
Chapter 12

Conclusions and recommendations

A decade ago, the Department of Families, Community Services and Indigenous Affairs (2007) introduced the Mental Health Community Based Programme (MHCBP) for families living with a family member with mental illness. This exploratory study examined the experience of families in the Headin’ Up program at Family Support Newcastle, one of the projects funded under the MHCBP. As well as tracking changes in mental health and family support policy, interviews and focus groups with family members, and family workers, respectively, constituted the main research focus.

The study revealed the importance of community-based family support services for families living with mental health issues. Most of the families in this study were on very low incomes and were receiving support from a number of agencies, not all of which employed the strengths-based approach of Family Support Newcastle. Thus stigma, even among service providers, was a barrier to recovery and family wellbeing. Even though stigmatising labels continued to be an issue for people living with mental illness, having a diagnosis was important, because the system allocated services on this basis. In some cases, a diagnosis helped parents to understand the symptoms which had been affecting them, and also helped them to speak with their children about their symptoms if they wished.

Ongoing community education is obviously needed to improve understanding of mental illness, and people’s capacity for clinical and personal recovery, including the capacity to parent their children. This should also be addressed in vocational and tertiary courses relating to mental health, child and family development, childcare, mental health promotion, and community development.

The lived experiences of family members comprised the findings of this study, and reflect the processes identified in the framework for personal recovery, including maintaining hope, and re-establishing identity (Australian Health Ministers’ Advisory
Council, 2013a). The policy changes toward recovery point to the central place of lived experience in the development of recovery-oriented approaches for mental health services. They are a victory for the service-user movement though have yet to be fully integrated into organisational practice (Davies, Gray, & Butcher, 2014; Gray, Davies, & Butcher, 2014). Hence stigmatisation and labelling remains a problem in the sector even though the National Institute of Mental Health in the USA has abandoned the DSM psychiatric classification system (Insel, 2013). This trend is likely to increase as mental health service users enhance public knowledge and awareness of the nature of mental illness.

The findings of this study support this trajectory as a major policy thrust being implemented in New South Wales, the context of this study, by the NSW Mental Health Commission (2014a, 2014b), which emphasises that people are at the centre of mental health reform in that state.

The medical model has long dominated formal mental health services and, as this study has shown, has led to a separation of mental health and community-based family support policies and services. Given the dominance of the medical perspective, this has marginalised community-based services with the bulk of resources expended on the costly formal bureaucratic mental health system. In this system the lived-experience perspective of the mental health consumer has mostly gone unheard (NSW Mental Health Commission, 2014b).

To highlight ownership of mental health as a community issue, the discipline of Mad Studies has developed to reflect this service-user, recovery-oriented, lived experience perspective that is gaining traction in mental health policy and practice (LeFrançois & Reaume, 2013). It highlights the importance of language in talking about mental illness, and in response consumers have created The MadQuarry Dictionary (Our Consumer Place, 2013), a consumers’ guide to the language of mental health. In the mental health field words and language are critically important, related as they are to stigma and self-stigma, and to discrimination, disempowerment and loss of self-esteem, reflected in the language of parent accounts here.

While the core philosophy of the recovery orientation is self-determination, this occurs in the context of care in the community, which includes relationships with family,
friends, and practitioners. The findings of this study, especially relating to the support model delivered by the Headin’ Up family support workers, highlighted the much-valued home visits and *in situ* guidance, and is a model worthy of emulation by community-based family support services. A strong community services sector needs to respond flexibly to the difficulties in day-to-day living for children and families living with mental illness. The family workers’ approach encouraged families to feel hopeful, parents to re-establish their identity, and feel encouraged to reclaim their personal strengths and take control of their lives, key aspects in recovery paradigms. Models which emulate the Headin’ Up program would be geared to the role-specific and cultural and language needs of different groups caring for a family member living with mental illness, including parents, partners, children, grandparents, and foster carers, who have to negotiate with one or more bureaucracies in procuring financial and medical entitlements for those in their care (see Chapter 2). Streamlined ‘one-stop’ community-based services would avoid duplication and overlap and remove barriers to family support and unwanted scrutiny. To address the lack of focus on child mental health issues, the Australian Government’s response to the review of mental health programs and services includes planned reforms to child mental health services, with a workforce support initiative as one of several interconnected activities (Department of Health, 2015). The national workforce support initiative is aimed at supporting service providers working with vulnerable children, as well as those working with the parents and families of these children. Parents and families are also acknowledged as needing mental health support, although the activities required to achieve this have not been set out (Department of Health, 2015). The overall emphasis of the Government’s response is ‘person centred care’ (Department of Health, 2015, p. 7) but whether or not this translates into community-based support for families will emerge over time. In the neoliberal lexicon, person-centred care tends to imply an individualistic managed care response rather than a holistic, ecosystems response at various levels of care. This person-centred care model is being implemented into an already fragmented system, where formal mental health care and formal and informal community-based care are lodged in two separate institutional sectors. This has not changed and does not augur well for the future unless service users and the recovery-oriented movement gain further traction in policy circles.
To provide further empirical support for the effectiveness of community-based mental health services for families, a longitudinal study tracking and monitoring policy developments and changes and their impact on families living with mental illness is needed. A study of this nature should involve widespread representation and consultation, and reflect the context-specific peculiarities of Australia’s states and territories. Social workers need to work closely with mental health consumer groups and the Mental Health Commission to lend their weight and experience to future policy and practice development. To date the mental health sector has emphasised treatment in costly hospital beds, spending funds that could be better directed to flexible, community-based care. Given the episodic nature of mental illness, this means a limited focus on ill-health among people living with mental illness in the community day to day, whose needs are overlooked in the absence of a strong community-based support service network. These support services are rendered through contracts with major service providers that have tendered for them. Within this competitive service environment, access to sound information on effectiveness is limited, as services are measured on the number of people assisted rather than the quality of the services provided.

To summarise, the recommendations arising from this study of support for children and families living with a family member with mental illness are:

1. Continuing education, including self-education, about mental illness for all members of the community so that children, their carers, including parents, grandparents and foster carers, understand the lived experience of symptoms and recovery, with this understanding including the interrelationship between parenting and mental illness.

2. Community-based programs that enable home visiting so that parents and their children who are isolated can be linked to settings where they can meet parents who are also looking for friendship and support, and a place to feel they belong.

3. Coordination among government departments to create one-stop settings so that negotiations required of parents, grandparents, foster carers, and others caring for children are streamlined.
4. The embedding of the principles of recovery from mental illness into everyday practice and service delivery so that people are respected for their lived experience, believe that they can be responsible for their goals and aspirations, and feel hopeful about the future.

Almost 25 five years ago, a generation, the rights of people with mental illness in Australia were formally acknowledged in the Burdekin Report (Human Rights and Equal Opportunity Commission, 1993). People born at that time may now be parents. Considering the prevalence of mental illness, a proportion of their children will have a mental illness, as will a proportion of the parents themselves, leading to grandparents and foster carers to care for them, in some cases. Since publication of the Burdekin Report, advocacy by many people with lived experience of mental illness has led to consultation with, and participation by, consumers and carers in policy and service development and research, and community support. In spite of this, the ‘struggle for recognition’ continues to prevail for many who are parents and carers, and children, as this study has shown. Those participating in this study did so in the hope that discussing their experiences would contribute to understanding, and would be helpful for other families in the future.
References

Notes: 1. Authors Amy, Harriet, Jennifer, and Karen have chosen to use first names only. The first three names are pseudonyms chosen by those authors. 2. Author k. valentine uses lower case in her publications.


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Appendix I: Literature search strategies

Appendix II: Role of NFSS Headin’ Up Family Workers in research project

Appendix III: Invitation to families to participate

Appendix IV: Semi-structured interviews for:

- Parents and children living with a family member with mental illness
- Parents and children who have a mental illness

Appendix V: Information statement for family workers, and consent form

Appendix VI: Questionnaires (6)

Appendix VII: Information statement for adult participants, and consent form

Appendix VIII: Information statement for young people, and consent form

Appendix IX: Information statement for children, and consent form
Appendix I

Literature search strategies

The 17 bodies of literature related to this thesis included:

i) Eight different population groups: presented in Chapter 2

ii) Four background theories: presented in Chapter 3 and 4

iii) Mental health policy and service provision – Federal: Chapter 5

iv) Mental health policy and service provision – New South Wales: Chapter 5

v) Family Support policy and service provision – Federal: Chapter 6

vi) Family Support policy and service provision – New South Wales: Chapter 6

iv) Methodology: Chapter 7 – various literatures

The strategies used to locate literature:

1. Searches of academic journals, and books, via data bases

Cinahl

Humanities and Social Sciences

Medline/Pubmed

PsychINFO

Psychology and Behavioural Sciences

Proquest

Proquest Dissertations and Theses

Sociology

Social Work

Web of Science
Terms used for the following searches for Chapter 2:

i) Parents with mental illness who have dependent children
parents; mental illness; dependent children; fathers; psychiatric illness

ii) Partners of parents with mental illness
Partners; parents; mental illness; psychiatric illness

iii) Children and young people of parents with mental illness
children; adolescents; young people; parents; mental illness; psychiatric illness

iv) Parents caring for children with mental illness
parents; children; care; parenting; mental illness; psychiatric illness

v) Siblings of children with mental illness
siblings; children; mental illness; emotional disturbance

vi) Grandparents parenting children of parents with mental illness
grandparents; grandmothers; health; mental health; social support; parenting; children; parents with mental illness; parents with psychiatric illness

vii) Foster carers of children with mental illness
Foster care; children; mental illness; mental disorder

viii) Aboriginal families living with a family member with mental illness
Aboriginal; families, mental illness; emotional wellbeing; spirituality

Terms used for searching literature relevant to Chapters 3, 4, 5, 6, 7 were specific to the related section of each chapter.

2. Grey literature: written and electronic information not available in academic publications, such as information about foster carers in the context of this study, locating the personal accounts in the books referenced in Chapter 2; Garvey (2008), on wellbeing
of Aboriginal people (Ch. 2); information about meetings and conferences, e.g. Slade (2015) ‘Grace Groom Memorial Oration’, which addressed recovery.

3. Websites: provided information about federal and state government policies and programs, mental health reports, statistics, Family Support Newcastle documents, documents concerning Aboriginal and Torres Strait Islander wellbeing (Dudgeon et al., 2014).

4. Google and google scholar search engines

5. Some references were gained from reviews of reference lists in key journal articles.

6. Theses and Dissertations: University of Newcastle data base, and linked data bases.

7. Publication biography: my previously completed research and publications informed identification of possible sources of literature, such as information about grandparents caring for their grandchildren (Cowling et al., 2015); personal accounts of living with mental illness, or caring for grandchildren of parents with a mental illness (in Cowling 2004, 2006, and Sved Williams & Cowling, 2008).

Only references in English were sought. No limits on publication dates were set.
Appendix II

Role of NFSS Headin’ Up Family Workers in research project

Family Support for Parents & Children Living with a Family Member with Mental Illness
Vicki Cowling,
The University of Newcastle

Aim of this research

To gain an in-depth understanding of the experiences of formal and informal support of families and children living with mental illness, and how their participation in the mental health community based program (Headin’ Up) influenced these experiences.

How the research will be conducted: Adults, young people and children who agree to participate will be asked to participate in two interviews – when they first join Headin’ Up, and again six months later or sooner if they leave the project. The interviews will be conducted by Vicki Cowling.

Role of Family Workers

1. Attend a meeting to ask any questions about the following documents relating to the research:
   a. Advertising flyer for project
   b. Information statements for adults, children and young people
   c. Questionnaires and interviews:
      i. A family background questionnaire to be completed once only by an adult
      ii. Other questionnaires to be completed by an adult when families first become participants in Headin’ Up and again six months later or sooner (questionnaires about: family relationships, managing family crises, family participation in planning, number and type of services involved, service coordination)
   d. Interview schedule: Semi-structured interviews will be conducted with adults and young people and children when they join the project, and again six months later, or sooner to explore their experiences of support from personal and organisational networks.

2. When a family is accepted to Headin’ Up project, the Family Worker is to give the family the advertising flyer.

3. The Family Worker to encourage families to contact Vicki with any questions they have about the research project, at any time during the project.

4. Family Workers be available to provide support if a family or family member becomes distressed.

   Vicki Cowling

   Phone: 4924 6054 (w)
Appendix III

Invitation to families to participate

To Families in the Headin’ Up Project at Newcastle Family Support Service

You are invited to be part of a research project about parents and children who live with a family member who has a mental illness.

The purpose of this research is to find out about any changes in support families and children experience through being part of the Headin’ Up project.

Families who have a Family Worker can participate in this research: this includes parents, children and young people in the family.

To help people decide whether or not they would like to participate they can receive some more information about the project, by contacting me.

The experiences and ideas of all the people who do agree to participate will be combined into a report that will help workers to understand the ways in which parents and children who live with a family member with mental illness already feel supported, and ways in which services could be improved. Individual people will not be identified in the report.

I am a student at The University of Newcastle and I am doing this research as I am very interested to know about the supports families and parents and children have, and their ideas about this. I have two Supervisors for my research: Professor Mel Gray and Dr Graeme Stuart.

Please contact me for more information about this research project or – speak with your Family Worker.

Phone: 4924 6054 (Please leave a message if I am not there to answer phone)
Email: Vicki.Cowling@newcastle.edu.au

Thank you for taking the time to read this information.

Vicki Cowling
Appendix IV

Semi-structured interviews

Families and Children Living with a Family Member with Mental Illness
Vicki Cowling, Student, School of Humanities and Social Science,
The University of Newcastle

Semi-structured interview for Parents and children living with a family member with mental illness

The following is an interview guide – the questions will be expressed in a way that is sensitive to the participant’s age

For children and young people - acknowledge their participation, ask if they have any questions. Explain audio recording, and the opportunity they will have to read transcript.

Please respond to the questions and tell me about your experiences in your own words ... there are no right or wrong answers

I understand a member of your family has a mental illness is this your
- parent
- child
- brother, sister

What do you understand about the illness?
- what it is called
- the symptoms or signs that tell a doctor that the person has a mental illness
- how these symptoms or signs affect the person with the illness
- how the symptoms may be treated

Has anyone:
- spoken with you about this illness
- explained what the symptoms are
- explained how they affect the person
- explained the treatment people may receive

When someone in a family has a mental illness this can sometimes affect the family in various ways. Is this something you notice in your family? Tell me about what you notice.

If you need advice, or someone to talk to who are you most likely to go to:

Prompts
- family, friends, neighbours
- someone you know who has had similar experiences
- support groups set up by people with similar experiences
- a health professional, such as doctor/general practitioner or counsellor

*Semi-structured I’view: Supports (1 – P&C FamMem). V.01 11-11-2008*
- a mental health professional such as psychologist, psychiatrist, social worker, counsellor
- someone who is a respected member of the community such as a spiritual adviser in the community or associated with a church
- someone who is an Elder in your community

Sometimes service providers work together with a family in planning services. Tell me about your experiences of working ‘together’ with an agency, or group of agencies.

Sometimes service providers/workers want to know what children and young people think about what is happening, and what is needed. Tell me about any experiences you have had with workers.

What sort of things help you to know where to go and who to speak with to get help.

What sort of things do you think make it difficult to know where to go or who to speak with to get help.

Is there anything else that you think we should know when people are working with families where someone has a mental illness?

**People in My Network**

(Participants will be asked to use a descriptor such as ‘aunt’, friend etc rather than identify people by name)
Semi-structured interview for Parents and children who have a mental illness

The following is an interview guide – the questions will be expressed in a way that is sensitive to the participant’s age

For children and young people - acknowledge their participation, ask if they have any questions. Explain audio recording of the interview so that no important information is missed, and the opportunity they will have to read transcript.

'Please respond to the questions and tell me about your experiences in your own words ... there are no right or wrong answers'.

This project is about the support family members experience when someone in their family has a mental illness. I understand that you have a mental illness.

When someone in a family has a mental illness this can sometimes affect the family in various ways. Is this something you notice in your family? Tell me about what you notice.

If you need advice, or someone to talk to who are you most likely to go to?

Prompts

- family, friends, neighbours
- someone you know who has had similar experiences
- support groups set up by people with similar experiences
- a health professional, such as doctor/general practitioner or counsellor
- a mental health professional such as psychologist, psychiatrist, social worker, counsellor
- someone who is a respected member of the community such as a spiritual adviser in the community or associated with a church
- someone who is an Elder in your community

Sometimes service providers work together with a family in planning services. Tell me about your experiences of working ‘together’ with an agency, or group of agencies.

Sometimes service providers/workers want to know what children and young people think about what is happening, and what is needed. Tell me about any experiences you have had with workers.

What sort of things help you to know where to go and who to speak with to get help.

What sort of things do you think make it difficult to know where to go or who to speak with to get help.

Is there anything else that you think we should know when people are working with families where someone has a mental illness?

Semi-structured I’view: Supports (2 – P&CMI)  V.01 1-11-2008
People in My Network

(Participants will be asked to use a descriptor such as ‘aunt’, friend etc rather than identify people by name)
Appendix V

Information statement for family workers, and consent form

Family Support for Parents and Children Living with a Family Member with Mental Illness

Information statement for the research project – Family Workers
Document Version No. 01 Date 19-4-2010

You are invited to be part of a research project about parents and children who live with a family member who has a mental illness. I am a social worker, and a student from the School of Humanities and Social Sciences in the Faculty of Education and Arts at The University of Newcastle, studying for a PhD (Doctor of Philosophy). I have two Supervisors for this research at the University, Professor Mel Gray and Dr Graeme Stuart.

Why is the research being done?

The purpose of this research is to find out about any changes in support families and children experience through participating in the Headin’ Up project at Newcastle Family Support Service, and the ideas Family Workers have about the involvement of families in Headin’ Up.

I am very interested in the Headin’ Up project because for over 15 years I have been working with families, parents and children where a parent has a mental illness, and have undertaken research on this topic.

The experiences and ideas of all participants in this research will be combined into a report that will give this important information to Newcastle Family Support Service, and to similar agencies. It will help professionals to understand the ways in which parents and children who live with a family member with mental illness already feel supported, and ways in which support services could be improved.
What choice do you have about participating?

Participating in this research is entirely your choice. Only people who give their informed consent will be included in the project. Whether or not you decide to participate your decision will not affect your relationship with NFSS or the researchers.

You may withdraw from the project at any time. You do not have to give a reason for withdrawing, and you have the choice of any information you have given not being used for the project.

What would you be asked to do?

You will be invited to participate in a focus group discussion where the following topics will be discussed:
- What has worked well for families in being part of Headin’ Up
- Service gaps and interagency issues that may affect support services to families
- Issues affecting a family’s participation in a research project such as this PhD
- Your impression of the impact of Headin’ Up on families
- You will be asked to maintain the confidentiality of the group discussion.

How will the information be collected?

I will ask your permission to audio record the focus group so that important information is not missed. You will receive a written transcript of this recording so that you can make any changes.

You will also be asked to complete a brief questionnaire that will ask: your age, gender, your professional qualification/s, your position title, and whether you work full time or part time.

How much time will it take?

The focus group will take one hour.

How might you feel while participating in the focus group?

While participating in the focus group, or following the focus group meeting, it is possible you may feel some anxiety. If this occurs, it is suggested you speak with your Supervisor, or a support person.

How will your privacy be protected?

The information collected will not have your name on it. The information relating to the research will be stored in a locked filing cabinet at all times.
How will the information collected be used?

The information collected will be used for a research thesis which will be submitted for my university degree. It will also be used to report the results of the research in articles published in professional journals relating to social work, so that the results of the research are passed on to other people to learn from.

Information will not be reported about individuals, but about the group of people who participate in the research.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or if you have questions, contact me on 4924 6054. Please leave a message if I am not there to answer the phone.

If you have any questions about the project please feel free to talk to me, or one of my University Supervisors.

Vicki Cowling, Student/Principal Researcher: 4924 6054
Professor Mel Gray, Supervisor: 4921 7732
Dr. Graeme Stuart, Supervisor: 4921 7241

Thank you for considering this invitation to participate in the research.

__________________________
Professor Mel Gray, Supervisor
_____________________________
Vicki Cowling, Student/Researcher

The project has been approved by The University of Newcastle Human Research Ethics Committee, Approval No. H2008-0430

If you have any concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, it may be given to me, the researcher. If an independent person is preferred, please make the complaint to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia. Telephone: 4921 6333.
Email: Human-Ethics@newcastle.edu.au
Family Support for Parents and Children Living with a Family Member with Mental Illness
Consent Form – Family Workers
Document version No. 01 Date 19/4/2010

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have kept.

I understand that I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to participating in a one hour focus group meeting and having it audio recorded.

I understand that my personal information will remain confidential to the researchers.

I have had the chance to have my questions answered to my satisfaction.

Name:______________________________________________________________

Signature: ___________________________________________ Date_____________

Phone number:
Home: ___________________ Mobile:_____________________

Consent Form Family Worker V.01 19.4.2010
Appendix III

Questionnaires

1. Family Background Questionnaire (FBQ), completed at the first interview only
2. MacMaster Family Assessment Device General Functioning subscale (FAD-GF)
3. Family Crisis Oriented Personal Scales (F-COPES)
4. Service Coordination (SC)
5. Family Participation in Planning (FPP)
6. Services your family may have been involved with
Family Background Information
CONFIDENTIAL

Answers to the following questions will help us compare characteristics of research participants with the same characteristics of the whole population

PART A: Questions about the family/household

<p>| | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1. Who lives in your household: Please tick boxes that apply to your household</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>One parent and child/ren</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Two parents and children</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Parent, partner and children</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Other family members</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Friends</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Other people – please specify</td>
<td></td>
</tr>
</tbody>
</table>

2. People living in the household including yourself - age, gender and mental illness

The aim of the Headin’ Up project is to support families and children where a family member has a mental illness. For family members listed who have a mental illness, please write the name of the illness. If you do not know the name of the illness please write ‘don’t know’.

<table>
<thead>
<tr>
<th>Age</th>
<th>Male/Female</th>
<th>Mental Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
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<td>7.</td>
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<td>8.</td>
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</tbody>
</table>
3. **What is the main language spoken at home?**

4. **Is your family of Aboriginal or Torres Strait Islander background?**

5. **What is the household income?** *Please tick one box*

   - [ ] Less than $30,000 per year
   - [ ] More than $30,000 per year

6. **What sort of housing do you live in now?** *Please tick one box*

   - Live in home/flat rented from Housing New South Wales
   - Live in own home/flat
   - Live in home/flat rented privately
   - Live in shared housing
   - Live in other housing

   **How many places has your family lived in over the past five years?**

**PART B: Questions about the main adult carer in the family**

1. **What country were you born in?**

3. **Current marital status:** *Please tick one box*

   - [ ] Married
   - [ ] Separated
   - [ ] De Facto
   - [ ] Divorced
   - [ ] Single

9. **What is your highest level of education?** *Please tick one box*

   Did you:
   - Complete Year 7
   - Complete Year 10
   - Complete secondary school
   - Attend further education or training after secondary school
   - [ ] Yes
## Family Self-assessment:
Please read the statements below and circle one of the responses

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>2. In times of crisis we can turn to each other for support</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>3. We can not talk to each other about sadness we feel</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>4. Individuals are accepted for who they are</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>5. We avoid discussing our fears and concerns</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>6. We can express feelings to each other</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>7. There is lots of bad feeling in the family</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>8. We feel accepted for who we are</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>9. Making decisions is a problem for our family</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>10. We are able to make decisions on how to solve problems</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>11. We do not get along well together</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>12. We confide in each other</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
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</table>


*Thank you.*
F-COPES – Family Problem Solving
Please read the statements below and circle one of the responses
When we face problems or difficulties in our family we respond by --

<table>
<thead>
<tr>
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<th>Please circle one of these responses</th>
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<tbody>
<tr>
<td>1.</td>
<td>Sharing our difficulties with our relatives</td>
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<tr>
<td>2.</td>
<td>Seeking encouragement and support from friends</td>
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<tr>
<td>3.</td>
<td>Knowing we have the power to solve major problems</td>
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<tr>
<td>4.</td>
<td>Seeking information and advice from persons in other families who have the same or similar problems</td>
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<td>5.</td>
<td>Seeking advice from relatives, for example - grandparents</td>
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<tr>
<td>6.</td>
<td>Seeking assistance from community agencies and programs designed to help families in our situation</td>
</tr>
<tr>
<td>7.</td>
<td>Knowing that we have the strength within our own family to solve our problems</td>
</tr>
<tr>
<td>8.</td>
<td>Accepting gifts from neighbours (e.g. food)</td>
</tr>
<tr>
<td>9.</td>
<td>Seeking information and advice from the family doctor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<td>9.</td>
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<tr>
<td>10. Asking neighbours for assistance</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
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<tr>
<td>11. Facing problems ‘head on’ and trying to get solutions right away</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>12. Watching television</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>13. Showing that we are strong</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>14. Attending services related to my religious or spiritual faith</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>15. Accepting stressful events as a fact of life</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>16. Sharing concerns with close friends</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>17. Knowing luck plays a big part in how well we are able to solve family problems</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>18. Accepting that difficulties occur unexpectedly</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>19. Doing things with relatives (get-togethers, barbecues, etc.)</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>20. Seeking professional counselling and help for family difficulties</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
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</tr>
<tr>
<td>21. Believing we can handle our problems</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>22. Participating in activities related to my religious/spiritual faith</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>23. Seeing the family problem in a more positive way so that we do not become too discouraged</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>24. Asking relatives how they feel about problems we face</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>25. Feeling no matter what we do to prepare we will have difficulty handling problems</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>26. Seeking advice from a minister of religion or spiritual leader</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>27. Believing if we wait long enough the problem will go away</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>28. Sharing problems with neighbours</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>29. Having faith in a religious or spiritual figure or place</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neither Agree nor Disagree</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>

F-COPES: Family Crisis-Oriented Personal Scales
F-COPES/Family Coping V.01 1-11-2008

Thank you
<table>
<thead>
<tr>
<th>Service Coordination</th>
<th>Please circle <em>one</em> of these responses --</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Service providers have worked together for me and my family</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>2. The workers from the different agencies seem to agree on a single plan for my child/ for me</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>3. The information received from various agencies/workers is contradictory</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>4. The staff from the different agencies disagree on what care my child should get / I should get</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>5. The staff from the different agencies have given me good information about my child’s care/ my care</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>6. When we have been referred to new providers/agencies the staff are aware of my child's situation/ my situation</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>7. When a new worker/service provider has become involved he or she is unaware of my child’s situation/ my situation</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>8. Staff members from one agency have helped me get services from other providers</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
<tr>
<td>9. There is no cooperation among the agencies/workers giving services to my child/ to me</td>
<td>Not True  A Little True Somewhat True  Mostly True Very True</td>
</tr>
</tbody>
</table>


*Thank you*
<table>
<thead>
<tr>
<th>Family Participation in Planning</th>
<th>Please circle one of the numbers -</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your involvement in planning services your family needs</td>
<td>No involvement 1 to High involvement 4</td>
</tr>
<tr>
<td>2. How much do you think your ideas are valued in planning services for your family</td>
<td>Not valued 1 to Highly valued 4</td>
</tr>
<tr>
<td>3. How would you rate your level of agreement in the plans that are made for your family</td>
<td>No agreement 1 to High agreement 4</td>
</tr>
<tr>
<td>4. How would you rate your role in planning for services your family is to receive</td>
<td>No role 1 to Significant role 4</td>
</tr>
<tr>
<td>5. How much would you say the needs of your whole family are considered when services are being planned</td>
<td>Not considered 1 to Very much considered 4</td>
</tr>
<tr>
<td>6. How would you rate the level of influence you are able to have in the planning process</td>
<td>No influence 1 to High level of influence 4</td>
</tr>
</tbody>
</table>


Thank you
Services Your Family May be Involved with such as:

*Please tick ‘Yes’ if you attend the service*

- General Practitioner: Yes
- Child and Family Health Nurse: Yes
- Community Health Centre: Yes
- Centrelink: Yes
- Child and Adolescent Mental Health Service: Yes
- Adult Mental Health Service: Yes
- Psychologist: Yes
- Department of Community Services (DoCS): Yes
- School Counsellor: Yes
- Carer Assist: Yes
- Samaritans: Yes
- Salvation Army: Yes
- Centacare: Yes
- Newcastle Family Support Service: Yes

Any other services you attend which are not listed above:

______________________________________________________________________
______________________________________________________________________

Services Used Q’aire V. 01 1-11-2008

*Thank you*
Information statement for adult participants, and consent form

Family Support for Parents and Children Living with a Family Member with Mental Illness

Information statement for the research project - adults
Document Version No. 01 Date 1-11-2008

You are invited to be part of a research project about parents and children who live with a family member who has a mental illness. My name is Vicki Cowling, and I am a student from the School of Humanities and Social Sciences in the Faculty of Education and Arts at The University of Newcastle. I am a social worker and I am studying for a PhD (Doctor of Philosophy) which means that I study a topic that we would like to learn more about, and complete a research project. I have two Supervisors for this research at the University: Professor Mel Gray and Dr. Graeme Stuart.

Why is the research being done?

The purpose of this research is to find out about any changes in support families and children experience through participating in the Headin’ Up project at Newcastle Family Support Service.

I am very interested in the Headin’ Up project because for over 15 years I have been doing research, and working with families, parents and children where a parent has a mental illness. The Headin’ Up project works with families like this, and also works with families where parents care for a child or young person with a mental illness, and with families where children have a brother or sister with a mental illness.
The experiences and ideas of all the parents and children and young people who agree to be part of this research will be combined into a report that will give this important information to Newcastle Family Support Service, and to similar agencies. It will help workers to understand the ways in which parents and children who live with a family member with mental illness already feel supported, and ways in which support services could be improved.

Who can participate in the research?

Families who have a Family Worker with the Headin’ Up project can participate in this project: this includes parents, children and young people in the family.

What choice do you have?

Participating in this research is entirely your choice. Only people who give their informed consent will be included in the project. If you or your children decide to participate or if you or your children decide not to participate this will not affect the services you receive.

If you decide to participate, and if you agree that your child can participate when your child wants to, you and your child may withdraw from the project at any time. You do not have to give a reason for withdrawing, and you have the choice of any information you have given not being used for the project.

What would you be asked to do?

If you agree to participate you will be asked to complete questionnaires about:
- how your family gets along together
- how your family faces problems or difficulties
- how much your family is involved in planning the services you receive
- the number of agencies working with your family
- how you think those agencies work together to support your family

You will also be asked to describe in your own words:
- what you understand about mental illness
- the ways in which adults and children may care for or support the family member who has a mental illness
- who you go to for support
- what is helpful or unhelpful in getting the support you need

The above information will be collected twice: when you first join the Headin’ Up project, and again six months later, or sooner if your family is no longer involved with the Headin’ Up project.

The following information will be collected only once: You will be asked to give information about your age, your gender, your level of education and family income (you will not be asked to give your actual income).

If you agree to participate I will arrange to meet you to complete the interviews.
What would your child be asked to do?

Your child will also be asked to describe in his or her own words:
- what they understand about mental illness
- the ways in which they believe they may care for or support their family member who has a mental illness, or the ways in which they feel supported
- who they go to for support
- what is helpful or unhelpful in getting the support they believe they need

The above information will be collected twice: when the family first joins the Headin’ Up project, and again six months later, or sooner if your family is no longer involved with the Headin’ Up project.

If children and young people agree to participate I will arrange to meet them to complete the interviews.

How will the information be collected?

You will be asked to reply to questions in the questionnaires listed in part 1 above. For part 2 you and your children will be asked to answer some questions in your own words and I will take notes about what you and your children say. I will also ask your permission to record the interview so that important information is not missed. You and your children will receive a written copy/transcript of this interview so that you can make any changes.

How much time will it take?

It will take about one and a half hours to answer the questionnaires and questions set out above at each of the two meetings. It may take longer if several children and young people in your family want to participate.

Is there a financial contribution to families for participating?

Each family will receive $20 in acknowledgement of your participation, and as a contribution to any travel costs involved. Ten dollars ($10) will be paid at the time of the first interview, and $10 at the time of the second interview.

How might you feel while answering the questions?

When completing the questionnaires and answering the questions you and your children may find that you are thinking about events in your family you may not have thought about before. These could be good memories, but may also be a reminder of difficult times you have had. If at any time you feel distressed, we will arrange to contact a support person of your choice, this may be your Family Worker, or someone else.
How will your privacy be protected?

Any information collected will not have your family name on it. A code number will be used instead. The information will be stored in a locked filing cabinet at all times. The list of code numbers will be locked in a place separate from the questionnaires. The code numbers will be removed from the questionnaires when the research project has been passed by The University of Newcastle, and will be destroyed. This is a rule of the University.

Are there times when my privacy may not be protected?

As a professional worker, and researcher, I need to respect and protect the privacy of people contributing to the research. There are two exceptions to this:

1. Where someone, during an interview, gives information which indicates that children are at risk of harm, this would be discussed with the family, who may like their Family Worker present. A report about the risk of harm may have to be made to the Department of Community Services.
2. Where someone, during an interview, gives specific details about a serious crime, the police may have to be informed.

How will the information collected be used?

The information collected will be used for a research thesis which will be submitted for my university degree. It will also be used to report the results of the research in articles published in professional journals relating to social work, so that the results of the research are passed on to other people to learn from.

Information will not be reported about individuals, but about the group of people who participate in the research.

How will I find out about the results of the research?

After families have completed the second interview I will send each family a written summary of results to let them know how results from the first and second interviews compare. This information will not be given to anyone else.

When the research has finished, a summary of the results for all families combined will be given to all people who have participated. This will be given to families in writing when the research has been passed by The University of Newcastle.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or if you have questions, contact me on 4924 6054. Please leave a message if I am not there to answer the phone.

If you would like to participate please telephone me on 4924 6054, or speak with your Family Worker.
Children participating in the research: Information for parents

If you are signing consent on behalf of a child or young person under 18 years of age, and they can understand what the research involves, please talk about the project with them, before deciding they can participate. Parents may consent to their child participating, but the final decision rests with the child or young person.

If you have any questions about the project please feel free to talk to me, or one of my University Supervisors, here are our phone numbers:

- Vicki Cowling, Student/Principal Researcher: 4924 6054
- Professor Mel Gray, Supervisor: 4921 7732
- Dr Graeme Stuart, Supervisor: 4921 7241

Thank you for considering this invitation to participate in the research.

Professor Mel Gray, Supervisor
Vicki Cowling, Student/Researcher

The project has been approved by The University of Newcastle Human Research Ethics Committee, Approval No. H2008-0430

If you have any concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, it may be given to me, the researcher. If an independent person is preferred, please make the complaint to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia. Telephone: 4921 6333. Email: Human-Ethics@newcastle.edu.au
Family Support for Parents and Children Living with a Family Member with Mental Illness

Consent Form - Adult
Document version No. 01 Date 1-11-2008

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have kept.

I understand that I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to:

- Completing questionnaires
- Participating in an interview and having it recorded

I understand that there will be two meetings for this research project – one at the beginning and one six months later, or sooner if we are no longer involved with the Headin’ Up project.

I understand that my personal information will remain confidential to the researchers.
I have had the chance to have my questions answered to my satisfaction.

I understand that I will receive information about results of the research as follows:

1. A written summary of responses for my family following the second interview
2. A written summary of responses for all families combined when the research has been completed.

Name:__________________________________________________________

Signature:______________________________________________________Date____________________

Phone number:

Home:_________________Mobile:______________________________
Appendix VII

Information statement for young people, and consent form

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Family Support for Parents and Children Living with a Family Member with Mental Illness

Information statement for the research project – for young people
Document Version No. 01 Date 27-01-2009

What is this research about?

This is an invitation to be part of a research project about young people, parents and children who live with a family member who has a mental illness, and this letter tells you about the project. The letter tells you why the research is being done, and how you can be part of it.

My name is Vicki Cowling, and I am a student at The University of Newcastle. I am a social worker and I am studying for a PhD (Doctor of Philosophy) which means that I do a research project about a topic we would like to learn more about. I have two Supervisors for this research at the University: Professor Mel Gray and Dr Graeme Stuart.

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Family Support for Parents and Children Living with a Family Member with Mental Illness

Information statement for the research project – for young people
Document Version No. 01 Date 27-01-2009

What is this research about?

This is an invitation to be part of a research project about young people, parents and children who live with a family member who has a mental illness, and this letter tells you about the project. The letter tells you why the research is being done, and how you can be part of it.

My name is Vicki Cowling, and I am a student at The University of Newcastle. I am a social worker and I am studying for a PhD (Doctor of Philosophy) which means that I do a research project about a topic we would like to learn more about. I have two Supervisors for this research at the University: Professor Mel Gray and Dr Graeme Stuart.
**Why is this research being done?**

I am doing this research to find out how being part of the Headin’ Up project at Newcastle Family Support makes a difference for young people and families – do they think they have more help and support after being with Headin’ Up.

I am very interested in the Headin’ Up project because for over 15 years I have been working with young people, children, parents and families where a parent has a mental illness. The Headin’ Up project works with families like this, and also works with families where parents care for a child or young person with a mental illness, and with families where children have a brother or sister with a mental illness.

I am interested in the ideas of all the young people and parents and children who agree to be part of this research.

The information collected during the research project will be put into a report that will give this important information to Newcastle Family Support Service, and similar agencies. It will help workers to understand the ways in which young people and parents who live with a family member with mental illness already feel supported, and ways in which support services could be improved.

**Who can be part of the research project?**

Families who have a Family Worker with the Headin’ Up project can be in this project: this includes children, young people and parents.

**What choice do you have?**

You can choose whether or not to be part of this research project. If you do agree I will ask you to sign a consent form at the back of this letter. This means that you have made your own choice to be part of the research.

If you change your mind during the project and do not want to be part of it any more, you can say so, and you do not have to give a reason. Any information you have already given may still be used for the project, or you may decide that you do not want the information used for the project – that is your choice.

**What would you be asked to do?**

If you agree, I will arrange with you and perhaps your parent to meet with you to ask you for your ideas about what has helped you and your family, and what you know about mental illness. Your ideas are important as they will help people to understand how help for families may be improved.
I will meet you twice – when your family first joins the *Headin’ Up* project, and again six months later, or sooner if your family is no longer involved with the *Headin’ Up* project.

**How will the information be collected?**

I will ask you to tell me what you think about the questions I ask, and I will take notes to help me remember what you say. I will also ask your permission to record the interview so that important information is not missed. I will give you a written copy of this information so that you can check it out and tell me if there are any mistakes.

**How much time will it take?**

It will take about an hour for each of the two interviews I need to do.

**How might you feel while answering the questions?**

While you are meeting with me some of the things we talk about may remind you of things you have not thought about before. These could be good memories, but may also be a reminder of difficult or unhappy times you have had. If at any time you feel upset, we will talk about what to do. We may arrange to contact a support person of your choice, this may be your Family Worker, or someone else.

**How will your privacy be protected?**

*Will anyone know what you have said?*

This is an important question. Any information collected will not have your name on it. A code number will be used instead. The information I have collected will be kept in a locked filing cabinet at all times. The code numbers will be locked in a separate place. The code numbers will be taken off the answer sheets when the research project has been passed by The University of Newcastle, and will be shredded. This is a rule of the University.

**Are there times when my privacy may not be protected?**

As a social worker, and a person doing research, I need to respect and protect the privacy of people who are part of the research. There are two times when I may not be able to do this:

1. If someone says something which makes me think that a child or young person is at risk of harm or injury. I would talk about this with the family, who may like to have their Family Worker present. A report about the risk of harm may have to be made to the Department of Community Services.
2. If someone, during an interview, gives specific details about a serious crime, the police may have to be informed.
How will the information collected be used?

The information collected will be used for a research report which will be submitted for my university degree. It will also be used to report the results of the research in articles published in professional journals about social work, so that the results of the research are passed on to other people to learn from.

Information will not be reported about individuals, but about the group of people who participate in the research. This is to protect people’s privacy.

How will I find out about the results of the research?

After young people and families have completed the second interview I will send each person a written summary of results to let them know how results from the first and second interviews compare. This information will not be given to anyone else.

When the research has finished, a summary of the results for all young people and families combined will be given to all people who have been part of the research. This will be given to families in writing when the research has been passed by The University of Newcastle.

What do you need to do to be part of the research?

Please read this Information Statement and be sure you understand what it says before you agree to participate and sign the consent form. If there is anything you do not understand, or if you have questions, contact me on 4924 6054. Please leave a message if I am not there to answer the phone.

If you would like to participate, please telephone me on 4924 6054, or speak with your Family Worker.

If you have any questions about the project please feel free to talk to me, or one of my University Supervisors, here are our phone numbers:

Vicki Cowling, Student/Principal Researcher: 4924 6054
Professor Mel Gray, Supervisor: 4921 7732
Dr Graeme Stuart, Supervisor: 4921 7241
Thank you for thinking about my invitation to be part of this research.

__________________________  ________________________________
Professor Mel Gray, Supervisor    Vicki Cowling, Student/Researcher

The project has been approved by The University of Newcastle Human Research Ethics Committee, Approval No._________________

If you have any concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, it may be given to me, the researcher. If an independent person is preferred, please make the complaint to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia. Telephone: 4921 6333. Email: Human-Ethics@newcastle.edu.au
Family Support for Parents and Children Living with a Family Member with Mental Illness

Consent Form: Young Person (14-18 years)
Document version No. 01 Date 27-1-2009

I agree to participate in this research project and have not been made to take part.

I understand that the project will be conducted as described in the Information Statement I have been given.

I understand that I can withdraw from the project at any time and I do not have to give any reason for withdrawing.

I agree to participating in an interview and having it recorded.

I understand that there will be two meetings for this research project – one at the beginning and one six months later, or sooner if we are no longer involved with the Headin’ Up project.

I understand that my family information will remain confidential to the researchers.

I have had the chance to have my questions answered to my satisfaction.
I understand that I will receive information about results of the research as follows:

1. A written summary of my responses following the second interview
2. A written summary of responses for all families combined when the research has been completed.

Name: ______________________________________________________________

Signature: ___________________________________ Date _________________________

Phone number:

Home: ___________________ Mobile: __________________________
Information statement for children and consent form

Family Support for Parents and Children Living with a Family Member with Mental Illness

Information statement for the research project – for children
Document Version No. 01 Date 27-01-2009

What is this research about?

This is an invitation to be part of a research project about children and parents who live with a family member who has a mental illness, and this letter tells you about the project. The letter is pretty long so maybe you might like to have someone read it with you. The letter tells you why the research is being done, and how you can be part of it.

My name is Vicki Cowling, and I am a student at The University of Newcastle. I am a social worker and I am studying for a PhD (Doctor of Philosophy) which means that I do a research project about a topic we would like to learn more about. I have two Supervisors for this research at the University: Professor Mel Gray and Dr Graeme Stuart.

Why is this research being done?

I am doing this research to find out how being part of the Headin’ Up project at Newcastle Family Support makes a difference for children and families – do they think they have more help and support after being with Headin’ Up.
I am very interested in the Headin’ Up project because for over 15 years I have been working with children, parents and families where a parent has a mental illness. The Headin’ Up project works with families like this, and also works with families where parents care for a child or young person with a mental illness, and with families where children have a brother or sister with a mental illness.

I am interested in the ideas of all the children, young people and parents who agree to be part of this research.

The information collected during the research project will be put into a report that will give this important information to Newcastle Family Support Service, and similar agencies. It will help workers to understand the ways in which children and parents who live with a family member with mental illness already feel supported, and ways in which support services could be improved.

**Who can be part of the research project?**

Families who have a Family Worker with the Headin’ Up project can be in this project: this includes children, young people and parents.

**What choice do you have?**

You can choose whether or not to be part of this research project. If you do agree I will ask you to sign a consent form at the back of this letter. This means that you have made your own choice to be part of the research.

If you change your mind during the project and do not want to be part of it any more, you can say so, and you do not have to give a reason. Any information you have already given may still be used for the project, or you may decide that you do not want the information used for the project – that is your choice.

**What would you be asked to do?**

If you agree, I will arrange with your parent so that I can meet with you to ask you for your ideas about what has helped you and your family, and what you know about mental illness. Your ideas are important as they will help people to understand how help for families may be improved.

I will meet you twice – when your family first joins the Headin’ Up project, and again six months later, or sooner if your family is no longer involved with the Headin’ Up project.
How will the information be collected?

I will ask you to tell me what you think about the questions I ask, and I will take notes to help me remember what you say. I will also ask your permission to record the interview so that important information is not missed. I will give you a written copy of this information so that you can check it out and tell me if there are any mistakes.

How much time will it take?

It will take about an hour for each of the two interviews I need to do.

How might you feel while answering the questions?

While you are meeting with me some of the things we talk about may remind you of things you have not thought about before. These could be good memories, but may also be a reminder of difficult or unhappy times you have had. If at any time you feel upset, we will talk with your parent about what to do. We may arrange to contact a support person of your choice, this may be your Family Worker, or someone else.

How will your privacy be protected?

Will anyone know what you have said?

This is an important question. Any information collected will not have your name on it. A code number will be used instead. The information I have collected will be kept in a locked filing cabinet at all times. The code numbers will be locked in a separate place. The code numbers will be taken off the answer sheets when the research project has been passed by The University of Newcastle, and will be shredded. This is a rule of the University.

Are there times when my privacy may not be protected?

As a social worker, and a person doing research, I need to respect and protect the privacy of people who are part of the research. There are two times when I may not be able to do this:

1. If someone says something which makes me think that a child is at risk of harm or injury. I would talk about this with the family, who may like to have their Family Worker present. A report about the risk of harm may have to be made to the Department of Community Services.

2. If someone, during an interview, gives specific details about a serious crime, the police may have to be informed.
How will the information collected be used?

The information collected will be used for a research report which will be submitted for my university degree. It will also be used to report the results of the research in articles published in professional journals about social work, so that the results of the research are passed on to other people to learn from.

Information will not be reported about individuals, but about the group of people who participate in the research. This is to protect people’s privacy.

How will I find out about the results of the research?

After children and families have completed the second interview I will send each person a written summary of results to let them know how results from the first and second interviews compare. This information will not be given to anyone else.

When the research has finished, a summary of the results for all children and families combined will be given to all people who have been part of the research. This will be given to families in writing when the research has been passed by The University of Newcastle.

What do you need to do to be part of the research?

Please read this Information Statement and be sure you understand what it says before you agree to participate and sign the consent form. If there is anything you do not understand, or if you have questions, ask your parent if you can contact me on 4924 6054. Please leave a message if I am not there to answer the phone.

If you would like to participate, and your parent has given permission, please telephone me on 4924 6054, or speak with your Family Worker.

If you have any questions about the project please feel free to talk to me, or one of my University Supervisors, here are our phone numbers:

Vicki Cowling, Student/Principal Researcher: 4924 6054
Professor Mel Gray, Supervisor: 4921 7732
Dr Graeme Stuart, Supervisor: 4921 7241
Thank you for thinking about my invitation to be part of this research.

__________________________  ______________________________
Professor Mel Gray, Supervisor  Vicki Cowling, Student/Researcher

The project has been approved by The University of Newcastle Human Research Ethics Committee, Approval No. H2008-0430

If you have any concerns about your rights as a participant in this research, or if you have a complaint about the manner in which the research is conducted, it may be given to me, the researcher. If an independent person is preferred, please make the complaint to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia. Telephone: 4921 6333. Email: Human-Ethics@newcastle.edu.au
Family Support for Parents and Children Living with a Family Member with Mental Illness

Consent Form: Child
Document version No. 01 Date 1-11-2008

I agree for my child to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement I have been given.

I understand that my child can withdraw from the project at any time and neither my child nor I have to give any reason for withdrawing.

I agree to my child participating in an interview and having it recorded.

I understand that there will be two meetings for this research project – one at the beginning and one six months later, or sooner if we are no longer involved with the Headin’ Up project.

I understand that my personal information will remain confidential to the researchers.

My child and I have had the chance to have our questions answered to our satisfaction.

Consent Form Child V.01 1-11-2008
NEWCASTLE | CENTRAL COAST | PORT MACQUARIE | SINGAPORE
The University of Newcastle  enquirycentre@newcastle.edu.au  T +61 2 4921 5000
Callaghan NSW 2308 Australia  CRICOS Provider Number: 00109J  www.newcastle.edu.au
I understand that my child will receive information about results of the research as follows:

1. A written summary of his/her responses following the second interview
2. A written summary of responses for all families combined when the research has been completed.

Parent's Name: __________________________
Signature: __________________________

Child's Name: __________________________
Signature: __________________________

Date: __________________________

Phone number:
Home: __________________________
Mobile: __________________________