Submission
to
House of Representatives
House Standing Committee on Family, Community, Housing and Youth
Inquiry into better support for carers

1. Executive Summary

Family members of people with mental illness bear social, emotional and economic costs in their roles as caregivers. Despite the value to the community as a whole that primary carers provide, including considerable economic savings, carers are still not afforded programs and services that equip them to better manage their caring role, nor are they adequately compensated for the valuable role they provide.

For carers of people with mental illness, prevailing stigmatising attitudes and ignorance of mental illness leads to social exclusion and public policy that is effectively discriminatory.

Too often consideration of carers and their needs end up with services that offer 'support'. This 'support' is too often lacking in substance and rigour.

Mental Illness Fellowship Victoria submits that interventions for family members and carers of people with mental illness ought to be subject to the same rigorous evaluation measures as other health interventions, that is, they ought to be able to demonstrate that they are effective, appropriate, efficient, accessible, safe, continuous, capable, sustainable, and sensitive and responsive to carer needs.

There is a growing body of international evidence for effective interventions for families of people with mental illness. The development and growth of interventions and services for families ought to reflect and build on this evidence.

Programs and services for people with mental illness ought to have at least one of the three following aims: 1) To better equip family members and carers to develop effective caring strategies; 2) To assist family members and carers to manage the impacts of mental illness on their own lives, including higher risk of the emergence of mental health problems in carers themselves; and 3) To provide services that compensate for the personal economic costs of the caring role and/or to provide pathways that mitigate the economic costs of caring.

With these overarching aims, Mental Illness Fellowship Victoria recommends the following priorities for action:

1. Review the definitions of disability in all legislation that ensures inclusion of people with psychiatric disability, especially legislation that provides support and assistance to people with mental illness and /or their families. Criteria for Disability Support Pension, Carer Allowance and Payments and Home and Community Care programs should be prioritised for immediate review.
2. Review carer leave entitlements in employment contracts and develop flexible leave options that recognise the episodic nature of mental illnesses and the

periodic need for significant leave to provide more intensive care at times of severe impairment for carers of people with severe and enduring mental illness.

3. Identify and adequately resource evidence-based best practice health promotion and education programs targeted to consumers and carers eg. Paying Attention to Self (PATS) program and Well Ways and Well Ways Duo (Dual Diagnosis) family education programs.
4. Fund the development and roll out of health promotion and education programs targeted to groups with specific needs, including siblings and partners of people with mental illness, carers of people with mental illness in indigenous communities and CALD communities.
5. Fund the development and dissemination of targeted information resources for family members and carers of people with mental illness.
6. Fund specialist counselling interventions for carers of people with mental illness.
7. Consider the establishment of incentive-based pathways for carers of people with mental illness to become part of the professional mental health workforce in various disciplines, and provide incentives for health service providers to systematically incorporate carer and consumer perspectives, into their service planning and review.
8. Consider the establishment and funding of a specialist legal service (or an extension of current mental health legal services) to assist families in the establishment of appropriate trusts and wills arrangements to provide for their loved ones with a mental illness.

The rationale for these recommendations is set out in the remainder of this submission.

2. Preamble

Mental Illness Fellowship Victoria (MI Fellowship) is a non-government not-for profit major provider of community-based services to Victorians with serious mental illnesses, including schizophrenia, bipolar disorder and other low-prevalence disorders and their families and friends. MI Fellowship provides psychosocial rehabilitation services (including home-based outreach, day programs, residential, Prevention and Recovery Care, respite and community care units), employment, education to people with mental illness as well as significant family health promotion and education services for carers of people with mental illness.

Our services are built around the vision of a society in which mental illness will be understood and accepted, where people with mental illness and their families will be afforded the same regard as those with physical illnesses and resources will be available to offer early interventions and state of the art treatment and support. These interventions will be so effective that long-term negative consequences of mental illness will have disappeared for the person and their family. People will no longer experience stigma and society will treat them with the same respect and dignity as any other person, and welcome and fully include them as community members.

In the year 2007-8, MI Fellowship delivered family education programs to 250 family members in Victoria and 960 Australia-wide through our affiliated Fellowships in each state and territory of Australia. 213 counselling sessions were delivered to carers in Victoria and our Helpline received 4,470 calls from carers seeking information, support and referral.

In 2007 Mental Illness Fellowship of Australia conducted a national survey of its state organisation's memberships, including many people with mental illness and their families.

People were asked to identify the top priority issues for people with mental illness and their families. With 2,268 survey respondents, after housing and employment, consumer and family education and support was identified as the number 3 priority issue of concern. A copy of the survey results is included as an attachment (Attachment 1).

MI Fellowship submits that specialised interventions for people with mental illness are required due to the particular challenges that mental illness pose to families and because of the considerable stigma that still surrounds mental illnesses, especially the spectrum of psychotic illnesses, including schizophrenia and bipolar disorder. These specialised interventions need to respond to the social, emotional and economic impacts of mental illness on families and carers.

MI Fellowship submits that specialised health promotion and educational interventions are required that provide families with accurate, up-to-date information about the causes and treatments of mental illnesses, that provide an understanding of the mental health system, that build families' coping strategies and that provide and build a support network.

We also submit that a lack of understanding of the nature of psychiatric disability in the community generally and reflected in public policy and legislation often has further negative consequences for carers of people with mental illness. Definitions of disability most often emphasize physical disability so carers of people with mental illness often do not meet eligibility for services available to other carers. An example is given later in this submission regarding eligibility for carer allowance and payments.

2. The impact of mental illness on families and carers

The experience of caring for a person with a mental illness has social, emotional and economic costs for families.

2.1 Social impacts
Families of people with mental illness are more socially isolated than their peers. One in five people will experience some form of mental illness in their lifetime. Consequently, this impacts on one in five families (sometimes with multiple individual members experiencing mental illness).

A number of factors contribute to this:
• Mental illnesses, especially schizophrenia and other low prevalence psychotic disorders, are among the most poorly understood illnesses. Also, a significant level of stigma surrounds mental illness which leads to shame and social isolation for families. Many people affected by mental illness choose not to share their diagnosis, even amongst extended family, for fear of the misunderstanding and the prejudice that can ensue.
• The physical and emotional burden of caring for someone with a mental illness in addition to the time that is frequently required reduces the opportunity for family members to partake in broader social and community activities.
• The behaviours associated with poorly managed mental illnesses are such that some families do not want others to witness them. In addition, some people with mental illness themselves, because of the nature of their illness, do not want visitors in the house or experience anxiety levels so high that families must keep the stimulation down for that person by not having visitors and/or not leaving the person alone.

Factors such as these necessarily further exacerbate social isolation.

2.2 Emotional impacts

Family members of people with mental illness have higher levels of depression and anxiety than the rest of the population. The emotional burden of caring for a person with a mental illness has particular challenges. Stressors specific to carers of people with schizophrenia (and which are likely to be common to other low prevalence psychotic disorders), include:

- Grieving the loss of hopes and dreams for the person with the illness.
- Feeling shame and guilt that the carer/family may have contributed to the cause.
- Difficulty in dealing with challenging behaviours and fear of personal safety.
- Fear of leaving the person alone, taking a holiday or having visitors often resulting in social isolation.
- Strain on marriages and partnerships.
- Shame, guilt, confusion and anger that siblings experience.

Factors that contribute to the emotional burden of carers of people with mental illness include:

- **The nature of psychiatric illnesses**

Initially, symptoms emerge in the form of complex behavioural changes which are confusing for both the person and other family members. Family conflict is typical, as different family members have different levels of understanding of the behaviours.

- **The difficulty of diagnosis and hence appropriate treatment and support.**

Commonly there is a long period, often years, between the emergence of symptoms and a diagnosis. Families often bear the burden of caring in isolation because the behaviour of the person experiencing symptoms has no apparent explanation.

- **Fear of suicide**

Families of people with mental illness often live in constant fear that their loved one may suicide. One in ten people diagnosed with schizophrenia suicide within ten years of diagnosis. Suicide rates are higher in some other low prevalence disorders, including bipolar disorder and borderline personality disorder.

2.3 Economic impacts

Economic costs of caring for people with mental illnesses include loss of earnings (due to the necessity to reduce work in order to undertake the role of carer), increased use of household resources, damage to assets, and increased cost of health care due to stress related issues of caring.

Additionally, the economic impact on the broader community includes the cost of carer welfare payments, loss of earnings and higher use of the health system (generally because of stress-related illnesses related to caring). The costs of caring for a person with a mental illness in Australia are significant. An estimated $207 million is lost in average weekly earnings (and therefore $58.5 million tax foregone on carers' earnings) because of reduced workforce participation by those caring for people with mental illness who have

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severe and enduring disability. If carers of people with all levels of disability from all psychiatric illnesses were included, this figure would exceed $1.6 billion.

3 Issues regarding the impact of mental illness on families and carers of people with mental illness

3.1 The experience of people with mental illness, especially a psychotic illness, is traumatising, frightening and unique.

Furthermore, the recovery from psychotic episodes can take many months and even years. Recovery requires service providers to have an understanding of the unique nature of the experiences of people with mental illness. Specialised knowledge is paramount. Recovery needs to include all levels of support possible – from clinicians to families and carers.

3.2 Families experience the direct impact of a loved one's mental illness

Families are being required to provide care in an era where deinstitutionalisation and clinical preference for treating people at home is the norm.

The role of the carer involves decision making not only at times of crisis but also for financial support, housing support, emotional support and case management. The practical and emotional burden which this creates in families is referred to in the literature as objective and subjective burden[1]. This in turn, has been shown to result in the diminished mental health and well-being of the caregivers or family members – increased anxiety and uncertainty[2], shock and fear and family members may blame themselves for the situation of the ill person[3]. Many research studies support this view[4],[5].

3.3 Information provided to families is often inadequate

What many in our community know of mental illness is drawn from negative and outdated stereotypes leading to stigma and loss of hope for the life and possibilities of the person with mental illness[6].

Knowledge about mental illness, in terms of causes, treatment, recovery and rehabilitation options have significantly advanced and improved in recent years. Services informed by best practice in the field conceptualise the causes and, therefore, treatment of and recovery from mental illness beyond solely medical explanations. Biological, psychological and social factors are now considered part of best-practice frameworks.

3.4 Family members are often seen as 'part of the problem' which alienates and causes further trauma.

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[1] Schene, A.H. Objective and subjective dimensions of family burden: toward an integrative framework for research. Social Psychiatry and Psychiatric Epidemiology 1990, 29

[2] Adamec C. How to live with a mentally ill person. 1996, New York: John Wiley and sons Inc.

[3] Marsh D. Families and Mental Illness: New Directions in Professional Practice. 1992, New York: Praeger Publishers

[4] Leff J. Working with families of schizophrenic patients. British Journal of Psychiatry, 1994, Vol 164

[5] Schene A.H., vanWindengarden B., Koeter M.W.J. Family caregiving in schizophrenia: Domains and distress, Schizophrenia Bulletin 1998 Vol 4

[6] Corrigan P. and Lundin R., Don't Call Me Nuts – Coping with the stigma of mental illness, 2001, Recovery Press, USA

The distress and frustration often experienced and displayed by families of people with mental illness can lead to them being labelled as 'part of the problem' rather than a key to recovery. Theories rejected by the carer movement because of this are still operating in many clinicians' minds – theories including Expressed Emotion and the Schizophregenic mother[7]. These theories are not founded on sound evidence, are blaming and increase families' stress, alienation and isolation.

3.5 Families are often excluded from treatment planning.

This exclusion keeps families out of the loop and reduces their capacity to provide a valuable supporting role to their loved one. Because of poorly understood confidentiality requirements, despite policy guidelines stating otherwise, many clinicians believe that providing information to the family is contrary to professional ethics. This further excludes family members and carers from any treatment plans and prevents them from offering professionals helpful and even essential information as well as gaining important education.

3.6 Education and support of families is not seen as 'core work' by the mental health sector.

Demand on clinicians' time is such that only the most exceptional clinicians provide additional support to families on top of their already heavy workload with people with mental illness. The services provided by the mental health sector, due to limited resources, are provided almost exclusively to people with a mental illness. As such, family members rarely receive the education and support they require for their own health and well-being.

3.7 The lack of affordable, permanent housing options impacts on families

The MIFA national survey mentioned above returned the finding that housing is the number 1 issue of concern for people with mental illness and their families. Whilst the current Commonwealth Government homelessness service review rightly focuses on people who are currently homeless, the imperative of prevention of new homelessness raises for us the fact that many people with mental illness are *at risk of future homelessness* because of their insecure and marginal housing. In this group we would include people with mental illness:

- living in private rental with affordability and support issues
- living in public housing with support issues
- living in situations of dependence (e.g. with ageing parents), where there is no 'tenure' as such and future security is not assured.

Our view is that people with mental illness are no different from the general population in terms of their need for housing (viz privacy, security, amenity, accessibility, a home that offers 'acceptability' to the resident), however they have very specific *support* needs. Availability of adequate and appropriate support is the critical determinant of whether the housing of a person with mental illness will be viable and sustainable over time.

Compelling evidence demonstrates that the 'support' needs of people with mental illness are essentially three:

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[7] Lefley H.P Expressed Emotion: Conceptual, Clinical and Social Policy Issues, Hospital and Community Psychiatry 1992 Vol 43 No 6.

- *Tenancy management* – flexible support around the administration of a tenure (lease, mortgage) and practical support to maintain and upkeep the property;

- *Clinical support* – medical and clinical services that are accessible in the local community and if need be, direct to the home;

- *Psychosocial support* - assistance with household administration, budgeting, relationship support (e.g. managing conflict with neighbours), accessing and participating in the resources of the local community.

MI Fellowship believes that the best prevention strategy against homelessness for people with mental illness is availability of housing that is affordable, secure, and packaged with coordinated support across these three dimensions.

The result of the lack of permanent, secure, affordable housing for people with mental illness means that people end up living with ageing parents by default. Whilst there is much goodwill and generosity form both sides in making this arrangement work, it contributes neither to improved health outcomes nor independence for the person with mental illness and places unnecessary burden on ageing parents who often have their own health concerns.

3.8 Families are not adequately assisted in future planning for their family member with a mental illness

Many ageing carers contact our organisation concerned about the future of their loved one (often in his/her 40s or 50s) living in the family home. This group lack independent living skills, including financial management skills, and where families have money to leave as an inheritance, they struggle to know how to set up their will to ensure the son/daughter with psychiatric disability is well provided for into the future. Families report that most legal services have no understanding of the challenges facing people with psychiatric disability and much money is wasted on seeking legal advice that is inadequate. (Some families have reported that legal services have made comment that the real motivation for the families' request is to minimise taxation on the inheritance). Families also report that current trustee services are overly legalistic and inflexible in their management of money to the detriment of their loved one with a mental illness.

Consideration ought to be given to establishing and funding a specialist legal service to assist families in the establishment of appropriate trusts and wills arrangements to provide for their loved ones with a mental illness.

4 Why are the needs of families and carers not being addressed?

Despite the dependent nature of the system on families to provide ongoing care and support, service delivery to families of people with mental illness designed to mitigate these outcomes is minimal. The availability of reliable, regular and evidence-based support for families of people with mental illness is rare. Typically, there are two types of education for families available either through the clinical mental health sector or the generic carer support sector.

4.1 Clinical Mental Health Services

Structured education provided by mental health services is family psycho-education. The primary focus of clinical mental health services is on the management of symptoms and

the prevention of relapse of the person with the illness. Whilst these programs are proven to be effective at reducing relapse rates for people with schizophrenia and bipolar disorder, and to be of benefit to the family[8], families' access to these programs is limited for two important reasons:

1. The model involves participation by the person with the mental illness. Hence, the participation of the family relies on the agreement to participate by the person with the illness. Given the inherent nature of mental illness this is often hard to achieve, resulting in recruitment to these programs being difficult and drop out rates an issue.

2. The person with the mental illness must be receiving clinical treatment at the time. Families seeking support outside of this are, in the main, not receiving quality, evaluated education.

In addition, education and support typically provided by clinical mental health services requires attendance over a two year period (McFarlane Model) or six months (Behavioural Family Therapy model). This is time-intensive for both family members and the person with the illness, generally at a time in the family's development that offspring are becoming independent and the need for parent involvement is tapering off. Many families find this difficult to cope with.

Programs are being implemented spasmodically throughout the mental health sector and as a rule require external project funding to enable the service to free up staff.

Literature in the field indicates that recruitment by mental health services to these programs is difficult. They surmise, that the issues raised above, contribute to this fact.

4.2 Generic carer services

Generic carer services struggle to provide accurate and up to date support to families of people with mental illness. Issues related to families of people with mental illness are often less well developed in this sector as is evidenced by the 2005 report prepared by Access Economics Pty Ltd for Carers Australia (The Economic Value of Informal Care). This report estimated that 2.6 million people in Australia were providing 1.2 billion hours of care for people who need assistance due to disability, chronic illness or old age, conservatively saving the economy $16 billion dollars annually. Although mental illness and related psychiatric disability represents 20% of the overall health burden in Australia, the report failed even to list psychiatric disability in its disability categories.

Many generic services have in recent times attempted to include carers of people with psychiatric disability through the appointment of specialist workers and the recent commitment of the federal government through the Council of Australian Governments (CoAG) process of significant funds for mental health, including respite funds for carers, has been welcome. However, the difficulties of operationalising those funds with agreed respite models has highlighted that generic carer services lack specialist knowledge of the issues facing carers of people with mental illness.

Prior to this recent commitment of funding through CoAG, local Commonwealth Carer Respite Centres differed in their views of whether their funding included services to carers

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[8] Dixon L., Stewar B., Burland J., Delahunty J., Lucksted A., Hoffman M. A pilot study of the effectiveness of the Family-to-Family Education Program, Psychiatric Services 2001 Vol 52

of people with mental illness at all. In Melbourne, for example, 3 of 4 metropolitan Commonwealth Carer Respite Centres funded participation of carers in Mental Illness Fellowship Victoria's Well Ways Family education program for carers of people with mental illness. One centre would not fund participation on the grounds that their funding did not include services for carers of people with psychiatric disability. Across the country, local interpretation of funding was similarly inconsistent.

Such inconsistency is another example of systemic exclusion of psychiatric disability within disability services that further disadvantages both people with mental illness and their families at significant social, emotional and economic cost.

4.3 The Mutual Support & Self Help movement

In the 1970s and 1980s, at the time of significant deinstitutionalisation, there was a considerable increase in expectations of the role families would play in caring for people with mental illness. As a result of this, a worldwide movement of mutual support and self help emerged that valued peer learning, peer support and the sharing and importance of the 'lived experience' of mental illness, both for consumers and carers. The 'expertise by experience' of people with mental illness and carers and was seen to both complement and challenge the professional expertise provided by mental health clinicians.

This movement resulted in the formation of local support groups. These were led by voluntary carers, most often monthly and often in family homes or local church or community facilities. The aim of these groups was to offer information, an understanding ear and peer support through a social network that decreased isolation.

The movement also facilitated the rise of carer advocates and some valuable formalised roles within mental health services have developed from these.

The emphasis through the 1990s and 2000s on evidence-based best practice in mental health services, the rapid rate of change in medications, our understanding of causes and treatments for mental illnesses and developments in mental health service delivery (particularly in Victoria, where a significant Psychiatric Disability Rehabilitation & Support Services sector has been developed), have all challenged the capacity of locally-based, volunteer led, unstructured support group meetings to provide up-to-date accurate information about mental illnesses and services. Many of these groups have now closed down, but very few services have developed to replace them and what they offered. The value of peer led services that offer 'the lived experience' are valuable contributions to effective treatment and health outcomes. These elements need to be incorporated into modern evidence-based interventions for carers, but in structured and accountable ways.

5. What is needed?

5.1 Accessible, timely access to information

Families and carers need to understand the experience of consumers. Assisting families to understand the physical and emotional experiences of people with mental illness allows them to develop strategies which best respond to their experiences. For effective counselling of these families and carers, the issues that relate to consumers are important factors to be well understood, effective counselling and support programs allow families to remain in a caring role.

Consequently, all the services accessed by families should be informed by the most up-to-date information about treatment. Well-informed and supported families are best able to provide an environment that gives the person with the illness the best possible chance of recovery and minimise the traumatic impact of mental illness on all family members.

Mental Illness Fellowship Victoria has developed a series of 35 fact sheets specifically aimed at carers which match clinical terminology with a description of observable behaviours that family members may have experienced and tips for effective interventions. A sample fact sheet, 'Understanding Bipolar Disorder' is attached (Attachment 2).

5.2 Family education and support
Families need access to information and education that is sensitive to the lived experience of caring, that offers a peer supportive social network and that models health promotion and recovery for family members from the impacts of mental illness.

Education and health promotion programs that are facilitated by trained and educated carers, that are run for multi-family groups thereby building a support network, and that are run outside of clinical services where families often feel undervalued, are an area of priority for families of people with mental illness.

There are few such health promotion programs around that have been evaluated for effectiveness and impact. The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) in a recent publication indentified six programs worldwide that included Australia's Well Ways[9]

Well Ways is a family health promotion and education program specifically designed for carers of people with mental illness. Over six years, it has been extensively impact evaluated and has shown consistent reductions of depression and anxiety in carers who participate in the program. The Well Ways suite now has three different programs. A description of these is attached (Attachment 3).

Specialist counselling services are equally needed to assist carers to develop effective strategies specific to their particular family situation. This counselling needs to be provided by people with specialist knowledge the lived experience of people with mental illness and consideration ought to be given to providing pathways for carers to become professional counsellors in this area.

Culturally ethno-specific programs are needed for people from linguistically and diverse communities and for indigenous communities. Different cultures have profoundly different cultural constructs of illness and mental illness. There needs to be a respectful and mutual understanding built between ethno-specific groups and service providers so that each can better understand and work with these varying cultural constructs. Such programs could be developed from already existing programs redeveloped for specific culturally specific groups.

Likewise, the experience for partners as carers of people with a mental illness, siblings and young people caring for a parent with a mental illness are particular and need

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[9] Froggart et al. Families as Partners in Mental Health Care: A Guidebook for Implementing Family Work. World fellowship for Schizophrenia and Allied Disorders (WFSAD): Canada, 2007, 11. Six programs worldwide are identified, in Canada, Europe, United Kingdom, United States, WFSAD delivered in developing countries, and Australia's Well Ways

particular interventions that respect the lived experience from these perspectives. Once again, adaptations of already existing evidence-based education and support programs could fulfil this purpose with adequate funding

5.3 Access to Financial Assistance
Accessing the Carer Allowance and/or Carer Payments: An example of how disability definitions exclude people with psychiatric disability and impact on the availability and accessibility of benefits

Criteria for carer allowance and carer payments include an assessment of the level of disability of the person being cared for that principally focuses on physical mobility. Part C of the claim form asks the carer to assess the day to day needs of the person they care for. The explanatory notes state: "Where the person's disability or condition is episodic or is only apparent at certain times, the question should be answered for when the person is not experiencing an episode or flare-up of the disability/condition".

Part C
Question 24: Does the person you care for
1 move around the house;
2 fall over indoors;
3 move to and from bed chair;
4 have difficulty hearing others;
5 have difficulty seeing clearly;
6 need help or attention during the night;
7 have loss of bladder and/or bowel control;
8 use continence aids or equipment;
9 use the toilet;
10 eat his/her food;
11 shower or bathe him/herself;
12 dress him/herself;
13 look after his/her grooming;
14 take care of his/her own medication;
15 take care of his/her own treatment)

Question 25: Does the person you care for
1 understand what you, the carer, says
2 understand what other people say
3 let others know how he/she feels and what he/she wants
4 know where he/she is
5 know whether it is morning/noon/night
6 remember things that happened today

Question 26: Does the person you care for
1 wander away or 'run away' from home
2 shout, scream, or threaten other people
3 physically harm other people
4 damage furniture, possessions or objects
5 laugh or cry without apparent reason
6 deliberately harm him/herself
8 have unusual, inappropriate or repetitive behaviours

From 'Claim for Carer Allowance and/or Carer Payment',
Centrelink, Australian Government

Given that the nature of mental illnesses is episodic, the requirement to answer each question for when the person is *not* experiencing an episode is equivalent to excluding carers of people with mental illness by definition.

For people with bipolar disorder, for instance, an episode of hypomania or mania will often include high risk behaviours (eg reckless substance use, reckless spending, sexual promiscuity, setting out on physically demanding tasks), will mean the person has little need for sleep and will be active all night and will seek high stimulation (eg loud music, phone conversations) which entirely disrupt the family home. When this behaviour is challenged, conflict, aggression and sometimes violence will ensue. For primary carers in such instances, a manic episode can last for many weeks or months. Similarly, in a depressive episode, a person may be unable to get out of bed and will need assistance to ensure nutritional requirements are met. When a person with bipolar is not in a hypomanic or depressive episode, he/she can often function as effectively as anyone else, with no particular care needs. For primary carers, there may be, for example, two six weeks periods in a year when the person is in an episode and has high care needs (to minimise risks resulting from high risk behaviour), but without flexible leave options the carer's capacity to participate in the workforce is compromised.

For people with Schizophrenia, outside of psychotic episodes there are often residual symptoms and impaired cognitive functioning that demand some care. During a prolonged period of psychosis, the person will have high care needs. Once again, the unpredictability of these episodic illnesses mean that primary carers have very high demands at times and less at others, but the consequences are that primary carers' capacity to participate in the workforce is compromised.

This look at the carer allowance and payments criteria is used only as an example of where a lack of understanding of psychiatric disability has a real impact on the accessibility and availability of supports and services to carers of people with mental illness that are effectively discriminatory.

Consideration ought to be given to flexible carer leave arrangements within industrial relations legislation that takes account of the episodic nature of mental illnesses and that provides greater opportunities for sustained participation in the workforce.

Further, mental health services in general are facing a shortage of skilled workers. Consideration ought to be given to financially-funded pathways for carers to become part of the professional workforce in various disciplines. Carers have expertise by experience and have considerable capacity to fulfil professional roles beyond those of 'carer advocates' which are too often tokenistic roles that are on the fringe of the mental health service system (this ought equally to be an aim for mental health consumers).

6 Concluding remarks

In addition to carer-specific interventions, considerable effort needs to be made in educating the community to build greater understanding and acceptance of people with mental illness and their families in the community. Stigmatising attitudes and the resulting discriminatory behaviour that comes form these attitudes result in lost opportunities for social and economic participation of people with mental illness and their families. Like interventions for families and carers, these mental health literacy programs ought to be evidence-based and rigorously evaluated for effectiveness.

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The inclusion of people with mental illness and their families and carers in all aspects of community life is the responsibility of all members of the community. Both mental health literacy programs and mental health promotion will contribute to better heath outcomes of the community as a whole and will contribute positively to minimising the impact of mental illness when it occurs. Without changes in public attitudes, including those of public policy makers, real changes that positively impact on the lives of people with mental illness and their carers will be less effective and the long term costs to the community considerable.

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