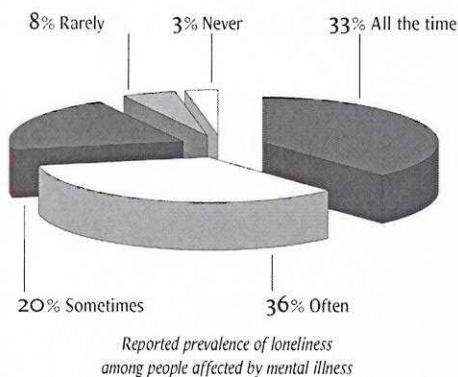# Research Report 1

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RESEARCH

Mental illness and social isolation

The first in a new series of SANE Research Reports asking people affected by mental illness to give their views on issues which affect their lives – providing real-world evidence to support advocacy for improved services and attitudes . . .

Relationships with other people matters to all of us. For people affected by mental illness, though, social isolation – a low level of interaction with others plus loneliness – is far more common. As well as being distressing, it also makes it harder for people to cope with symptoms and any effects of psychiatric disability. This SANE Research Report investigates the extent of social isolation and its impact on people with a mental illness.

The survey was conducted in February and March 2005, using a convenience sample of 258 consumers and carers who completed a questionnaire face-to-face, by telephone or via the SANE website. The survey was intended to answer four key questions . . .

How common is loneliness among people with a mental illness?

8% Rarely   3% Never   33% All the time

20% Sometimes   36% Often

Reported prevalence of loneliness among people affected by mental illness

The prevalence of loneliness reported was dramatically higher among respondents than in the general population. While around 10% of the population as a whole report feelings of loneliness (Victor et al, 2002), over two-thirds of those affected by mental illness reported feeling lonely 'often' or 'all the time'.

Does mental illness make it harder to maintain close relationships?

8% No change   7% Easier   55% Much harder

30% A bit harder
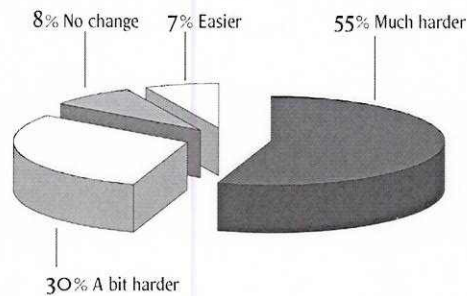
Reported difficulty maintaining close relationships among people affected by mental illness
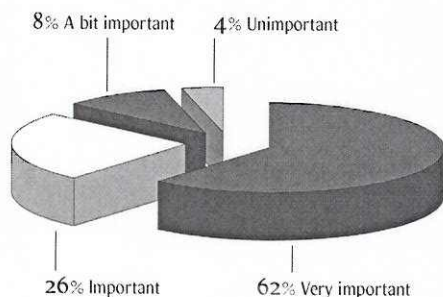
People overwhelmingly find it more difficult to maintain close relationships after being affected by mental illness. Around 85% reported that it was 'a bit' or 'much' harder, with 8% reporting no change and 7% saying it was easier.

Having a mental illness can make it harder to maintain relationships for a variety of reasons. Stigma and misunderstanding in the community about mental illness can mean people are reluctant to engage with those affected.

'The minute someone knows you have a mental illness, you are treated differently,' commented one respondent.

Social anxiety and symptoms, such as paranoia, can also affect the ability to communicate and get on with others easily. Having a low income is another important factor contributing to social isolation. Living on a welfare benefit such as the Disability Support Pension simply does not allow much money for social activities.

Mental illness and social isolation

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How important are social relationships to managing one's mental illness?

8% A bit important   4% Unimportant


26% Important   62% Very important

Reported importance of social relationships to managing mental illness

Friendships and social relationships are valued highly by people affected by mental illness, in helping them to manage symptoms and look after themselves. This may include practical support, people to socialise with and – very importantly – simply having someone to talk to about how they feel. Family members are especially important in fulfilling this role.

Almost 90% of respondents considered social relationships to be 'important' or 'very important' in helping to manage the effects of mental illness and maintain mental health.

How often do people affected by mental illness use community support services?

7% Often   7% Very often

14% Sometimes

26% Rarely   46% Never
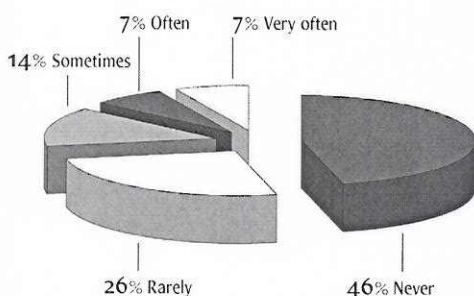
Reported use of community support services by people affected by mental illness

Despite their important role, support services such as rehabilitation programs are little-used because of limited supply and lack of referral – 72% used them 'rarely' or 'never'.

This is very concerning as there is a significant association between attendance and feeling less lonely and being able to manage one's illness better. Another concern noted was that many programs do not provide pathways to integration with the local community, and may actually perpetuate isolation from society by their insularity in service provision.

Recommendations

1 REHABILITATION PROGRAMS

Urgent action is needed by the Australian and State governments to implement a systematic national network of recovery-based rehabilitation programs, as an integral part of the National Mental Health Strategy.

2 IMPROVED REFERRAL BY CLINICAL SERVICES

A primary reason for limited use of rehabilitation programs is the lack of referral by clinical services. Doctors and other health workers need training and support to refer people to rehabilitation and other community support services as part of their normal practice.

3 SUPPORT FOR FAMILY AND OTHER CARERS

Evidence-based education, training and support for family and other carers needs to be implemented as an integral part of the National Mental Health Strategy.

4 TRAINING AND SUPPORT

Improved training and support is needed for workers in community support programs, so that they are able to provide more effective, evidence-based rehabilitation and promote integration with the local community.

5 ACTION TO REDUCE STIGMA

Renewed efforts are needed to improve understanding of, and attitudes towards, people affected by mental illness – encouraging a more inclusive community.

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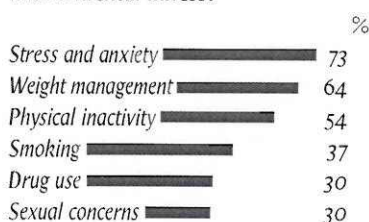# Research Bulletin 2

Mental illness and keeping well

*People affected by mental illness have serious concerns about their general health,
are active in trying to improve it, but face significant access and cost barriers to doing so . . .*

Keeping well is especially important for people affected by mental illness, because of generally poorer physical health, and because being healthier helps people to cope better.

This SANE Research Bulletin investigates the general health concerns of people with a mental illness, and what they find helpful in keeping well.

The survey was conducted in September and October 2005, using a convenience sample of 261 consumers and carers who completed a questionnaire face-to-face, by telephone or via the SANE website. The survey was intended to answer four key questions . . .
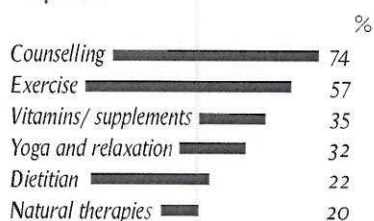
What are the main health concerns of people with a mental illness?

	%
Stress and anxiety	73
Weight management	64
Physical inactivity	54
Smoking	37
Drug use	30
Sexual concerns	30

These concerns reflect the poor physical health of people with a mental illness. Being overweight and having a poor diet, physical inactivity and smoking are major factors contributing to the poor physical health of people with a mental illness, who have a mortality rate 2.5 times higher than the norm (Coglan, R. et al, 2001. *Duty to Care: Physical illness in people with a mental illness.* University of Western Australia).

While only 12% of respondents reported being diagnosed with an anxiety disorder, six times this number expressed concern about stress and anxiety – indicating a great need for treatment and support in this area.

What do people with a mental illness do to keep well?

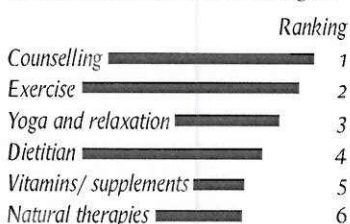|	%
Counselling	74
Exercise	57
Vitamins/ supplements	35
Yoga and relaxation	32
Dietitian	22
Natural therapies	20

Most respondents had tried strategies to keep well in addition to prescribed medication. The most common strategy was counselling from a psychologist, reflecting the high level of co-morbid anxiety reported.

Over 57% of respondents had tried to be more physically active. This may reflect concerns about being overweight, associated with antipsychotic medication as a side-effect, as well as with poor diet and physical inactivity. The use of self-prescribed vitamins and alternative therapies was also high, in line with their popularity in the general population.
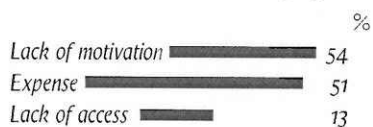
How effective are these strategies?

	Ranking
Counselling	1
Exercise	2
Yoga and relaxation	3
Dietitian	4
Vitamins/ supplements	5
Natural therapies	6

After counselling, exercise was ranked as the most helpful strategy for keeping well. This confirms the known importance of regular exercise to improving mental as well as physical health. Almost half of the sample did not exercise, however, and inactivity remained a major cause of concern for people.

While vitamins, supplements and natural therapies were tried by up to a third of respondents, these were ranked by them as the least effective.

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Mental illness and keeping well

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What are the barriers to keeping well?

%

Lack of motivation ▰▰▰▰▰ 54
Expense ▰▰▰▰▰▰ 51
Lack of access ▰▰▰ 13

The majority of respondents reported that they would like to be doing more to live a healthier life. Three main factors were reported as barriers which prevented this.

Difficulty with motivation is a serious symptom-related issue for many people with a mental illness. The effect of this on long-term physical and mental health is serious, and emphasises the role of health and community support workers in actively supporting people to keep well.

Expense and difficulty with access were the other major barriers reported. The cost of visiting a psychologist for counselling or joining a gymnasium or yoga class, for example, is prohibitive for many people on a low income.

A major contributor to lack of access is the failure of many health professionals to refer people to services which promote better health. Lack of physical activity, high smoking rates, poor diet and being overweight or obese are all contributors to the high levels of diabetes, heart disease and cancer among people with a mental illness. Physical health screening should also be a part of routine treatment, so that any problems can be diagnosed and treated, as as well as to encourage preventative action.

In summary

■ The most common health concerns of people with a mental illness are dealing with high levels of stress and anxiety, and being overweight and physically inactive.

■ Counselling and exercise are the most popular ways of trying to improve health, with significant numbers also using complementary therapies.

■ Respondents found counselling and exercise most effective, and the complementary therapies least effective.

■ Barriers to keeping well are symptom-related difficulty with motivation, expense, and difficulty with access (including lack of referral by health professionals).

Recommendations

1 PHYSICAL HEALTH SCREENING

Despite the acknowledged poor physical health of people with a mental illness, screening of this is not a part of routine treatment. Physical health screening needs to be integrated or coordinated with mental health treatment, to prevent as well as to treat any undiagnosed conditions such as diabetes, cancer or heart disease.

2 REFERRAL BY CLINICAL SERVICES

The most effective way to help people with a mental illness keep well is referral by health professionals to programs and services which promote an active, healthy lifestyle. Health professionals need training and support to ensure this becomes part of routine practice.

3 HEALTHY LIVING PROGRAMS

Rehabilitation programs, day centres and other resources used by people with a mental illness need support to promote healthy lifestyles. This can be done through education programs (on diet and quitting smoking, for example) through facilitating access to community resources such as gyms and swimming pools, and through their day-to-day activities (by promoting a healthy diet and regular outdoor exercise, for example).

4 ACCESS TO PSYCHOLOGICAL TREATMENTS

The Better Outcomes in Mental Health *initiative allows GPs to refer people for up to* 12 *sessions of counselling with a psychologist, covered by Medicare. However, many people affected by mental illness do not receive these psychological treatments which could have a dramatic effect on symptoms of depression and anxiety. Action is needed to ensure these treatments are provided to all those who would benefit from them.*

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Research Bulletin 3

Employment and mental illness

A lack of suitable, flexible part-time work is the major barrier to employment, say people affected by mental illness, and an understanding, supportive employer is the most important factor in keeping a job ...

For people affected by mental illness, employment brings not only an income, but also the dignity of having a recognised, valued place in society. Support is often essential for people to find and retain a job, especially under the new Welfare-to-Work rules.

This SANE Research Bulletin investigates the barriers to employment for people with a mental illness, and what they find helpful in gaining and keeping a job.

The survey was conducted during March and April 2006, using a convenience sample of 284 people with a mental illness who completed a questionnaire face-to-face, by telephone or via the SANE website. The majority of respondents were female (70%), with the most common diagnoses being depression (45%), bipolar disorder (18%), schizophrenia (14%) and anxiety disorder (7%). Three-quarters of respondents lived in urban areas, and 38% were smokers. Being a smoker has implications for employment, with the introduction of stricter legislation covering smoking in or near a workplace.

How many people work or want to work?

	%
In paid employment	57
In volunteer positions	7
Unemployed – want to work	17
Unemployed – unable to work	19

Over half of those surveyed were currently working, and 81% of the total were either in employment of some form, or wanted to work. This finding confirms how highly people affected by mental illness value employment, and are motivated to return to work – affirming the need for adequate support programs.

What are the main barriers to finding work?

	%
Lack of suitable work	53
Lack of training	14
Lack of support: finding work	14
Lack of support: on-the-job	13
Other	11

*more than one category could be selected

Having a mental illness can make it difficult to work full-time, and part-time work is often more suitable. Over half the respondents, however, reported difficulty in finding suitably flexible jobs.

Lack of training and support to find and retain work were also significant factors cited. This suggests insufficient access to specialist disability employment agencies which can provide support, and also the need for recovery-focused rehabilitation programs to provide more practical work-skills training.

What support helps people stay in work?

	%
Support from employer	49
Flexible work arrangements	42
On-the-job support from agency	3
Job club meetings	3
Other	3

A significant finding of this survey is that the most important factor in successful employment was a supportive employer – respectful, understanding and flexible about work arrangements. This rated far higher than technical interventions such as on-the-job support from an employment agency. Having a supportive employer also makes disclosure of having a mental illness easier.

This finding emphasises the need for education of the general population and especially employers and managers, so that workplaces are more welcoming and understanding of people with a mental illness.

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Is it helpful to disclose a mental illness?

	%
Disclosed to employer	57
Did not disclose	43

The majority of those who had ever worked, (57%) reported that they had disclosed their mental illness to an employer. Of these, 67% said that disclosing had been helpful because it provided a more understanding work environment, made getting support easier, and meant they were less worried at work.

The main reasons given for not disclosing were embarrassment and fear of discrimination by employers or others at work – not wanting to risk losing their job or to be treated differently simply because they had told someone they had a mental illness.

In summary

- Employment is highly valued by people with a mental illness, the great majority of whom want to work and contribute to society.

- Lack of suitable part-time and flexible work was reported as the primary barrier to getting back to work. Insufficient or inadequate support from employment agencies in finding and keeping a job was also cited.

- The most important factor in successful employment was a supportive employer, especially regarding flexible work arrangements.

- Most respondents had disclosed their illness to their employers, and had found this helpful in producing a more supportive work environment, and in reducing stress.

Recommendations

1 REMOVE BARRIERS

Employers need encouragement and incentives to provide flexible work arrangements, so that it's easier to employ people affected by mental illness. This may involve financial incentives as well as training for managers.

2 ONGOING SUPPORT TO FIND AND KEEP A JOB

Improved understanding of, and attitudes towards, mental illness by employers is a major factor in helping those affected to successfully get and keep a job. This support needs to be fostered and encouraged by education about mental illness and how to manage issues related to it – for employers, managers and work colleagues.

3 IMPROVE ACCESS TO EMPLOYMENT AGENCIES AND REHABILITATION SERVICES

Specialist disability employment services need to be better supported to place people with a mental illness in sustainable jobs, and to provide them with ongoing support. Improved access to rehabilitation programs that focus on the employee's recovery is also important to provide people with a mental illness practical work-skills.

4 MAKE IT EASIER TO DISCLOSE

Employer attitudes to mental illness are likely to reflect those in the general workforce and community. Action to reduce stigma in the wider population, as well as amongst employers, managers and work colleagues can therefore play a significant role in promoting employment for people with a mental illness. Workplace Equal Employment Opportunity (EEO) policies and staff training in these policies are an important starting point.

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Research Bulletin 4

Stigma and mental illness

Three out of four people affected by mental illness report they have experienced stigma, and believe tackling media misrepresentation is the best way to combat it . . .

People affected by mental illness can do without stigma – inaccurate, prejudiced assumptions that they are comical or violent or somehow less deserving of respect. These attitudes are not only hurtful, they also contribute to social isolation, a reluctance to seek help, and discrimination.

This SANE Research Bulletin investigates stigma against people with a mental illness, and how they think it should be tackled.

The survey was conducted during September 2006, using a convenience sample of 357 people with a mental illness who completed a questionnaire face-to-face, by telephone or via the SANE website. Three-quarters of respondents lived in urban areas. The majority were female (74%), with the most common diagnoses being depression (42%), bipolar disorder (22%), schizophrenia (15%) and anxiety disorder (9%). This sample profile is typical of respondents to other surveys in the SANE Research Bulletin series.

### How many people have experienced stigma?

26% No experience of stigma

74% Experience of stigma
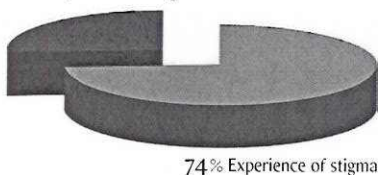
Three-quarters of the sample reported that they had personal experience of stigma (down slightly from 80% in 2004). They had experienced this in the attitudes of health and government workers, in the media, and in the general community. It is notable that 13% felt they had experienced stigma from staff in a health service, and 16% reported stigma in their place of work.

How important is it to reduce stigma?

4% Not important
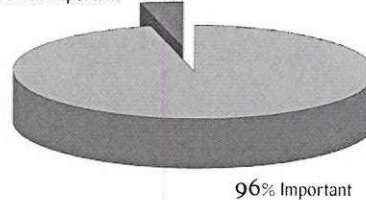
96% Important

Unsurprisingly, almost the entire sample agreed that it was important to reduce stigma.

The reasons given emphasise the social isolation and distress caused by stigma, in addition to the direct effects of mental illness.

Respondents said a reduction in stigma would help them to:
- feel better about themselves
- manage their illness better
- get back to work or study, and
- join in social activities.

Are attitudes changing?

37% Attitudes about the same
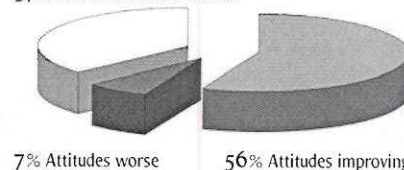
7% Attitudes worse   56% Attitudes improving

Some felt that stigma towards people with a mental illness was not changing and 7% considered it were getting worse – nevertheless the majority (56%) felt that attitudes were slowly improving, with 9% reporting that they were 'much better'.

Stigma and mental illness

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How can stigma be reduced?

Respondents were optimistic that stigma could be reduced, with suggestions spread across a whole range of initiatives in the community.

Tackling stigma in the media was seen as the most urgent priority (17%), reflecting the enormous influence of the media on community attitudes as a whole. The SANE StigmaWatch initiative was recognised by almost half of respondents as active in this area.

Education about mental illness in schools and in the workplace, as well as in the general community, was also highlighted as an important ongoing measure to reduce stigma.

An important barrier to stigma reduction is the fact that vilification of people with a disability – including those who have a psychiatric disability because of mental illness – is not unlawful in Australia (except under Tasmanian legislation).

While people cannot be publicly ridiculed because of their religion or sexual preference, journalists, advertising agencies and anyone else is free to mock and invite contempt for people with a mental illness or any form of disability.

SANE regards this lack of equality under the law as discriminatory, and is working with other organisations to bring about changes to State and Federal legislation on this issue.

In summary

- Stigma is common. Three-quarters of respondents said they had experienced it.

- Almost all respondents agreed it was important to reduce stigma, and that this would have a significant effect on improving their quality of life.

- Attitudes towards people with a mental illness are slowly improving, most respondents said, but there is a long way to go – with some feeling that attitudes are actually worsening.

- There was optimism among respondents that stigma could be reduced, with the media a primary target because of their influence over community attitudes.

Recommendations

1 EDUCATE THE MEDIA

The primary importance of the media in influencing public attitudes emphasises the need to maintain and develop initiatives such as the Mindframe National Media Strategy to educate the media. There is also a need to target specific groups such as advertising agencies and producers of television drama who are 'repeat offenders' in promoting stigma.

2 SUPPORT PEOPLE TO COMBAT STIGMA

People affected by mental illness are often distressed and disempowered by stigma, feeling misunderstood and excluded by society. The SANE StigmaWatch initiative should be continued, as a rare channel for them to convey the effect of stigma and help educate the media to be more accurate and respectful when depicting mental illness.

3 EDUCATE THE COMMUNITY

Changing community attitudes towards people with a mental illness means a commitment by government to supporting long-term action in public education – especially in important target groups such as schools – through the MindMatters initiative, for example – and in the workplace.

4 ANTI-VILIFICATION LEGISLATION

The national Disability Discrimination Act and State Equal Opportunity Acts should be amended so that people with a disability, including people with a mental illness, have the same protection from vilification as others do on the grounds of religion or sexual preference.

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Research Bulletin 5

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RESEARCH

Family carers and mental illness

Families play a major role in providing day-to-day care for people with a mental illness, but improved support is urgently needed, especially in education for this role . . .

Families play a major role in providing day-to-day care for people affected by mental illness. A number of government policies and initiatives have been aimed at helping this group over the years, including the recent COAG National Action Plan on Mental Health. Nevertheless, they are still very often unsupported, given no training to help their family member or themselves, and have important information withheld without reason by health professionals.

This SANE Research Bulletin investigates the effects of caring for someone with a mental illness, and what needs to be done to support families in this role.

The survey was conducted during March-April 2007, using a convenience sample of 529 family carers who completed a questionnaire via the SANE Helpline or website. Respondents were most commonly parents (30%), adult children (26%), partners (23%) or siblings (10%). The most common diagnosis of the person cared for was schizophrenia (36%), followed by bipolar disorder (23%) and depression (20%). Around one in four (23%) had a diagnosis of a mental illness themselves.

What is the impact of being a family carer?

56% Health worse
44% Health not worse
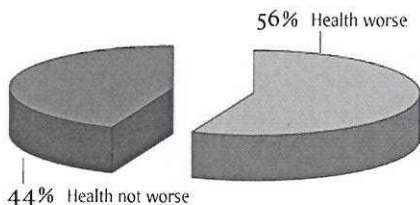
The majority of family carers (56%) reported that their physical and mental health had suffered as a result of their caring role. Many expressed frustration and anger that mental health professionals did not consult them about taking on this role, did not give any training or support, and disregarded and excluded them from treatment planning.

What difficulties are faced by family carers?

72% No support for family member
22% Family member receiving support
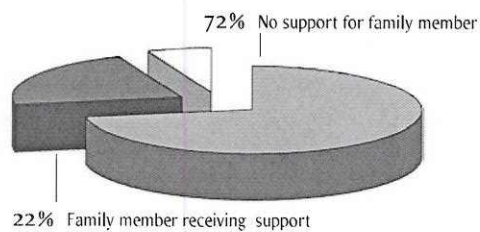
Families face an enormous, unfair burden of care, with almost three-quarters of family members with a mental illness (72%) not receiving any rehabilitation or community support. Fifty per cent had trouble finding suitable accommodation for their relative with a mental illness. Around half also experienced verbal aggression from their relative, and 25% had experienced physical aggression.

The majority (55%) expressed deep frustration at the lack of support and information from mental health professionals, especially where 'confidentiality' was inappropriately cited as a reason for excluding them.

What support had family carers accessed?

70% No training or education
30% Some training or education
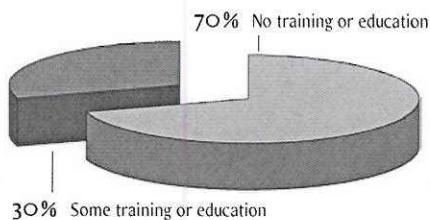
The majority (70%) had never received any form of training or education to carry out their role. Over half (54%) had not accessed carer support services of any kind. Around one-third (32%) had used the Internet to find information, and 5% had used a telephone helpline.

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Family carers and mental illness

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What help do family carers need?

79% More day-to-day support

21% Other
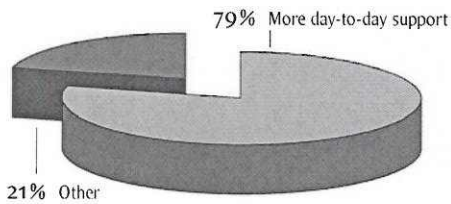
Family carers expressed an urgent need for practical, day-to-day support to ease their role. They asked to be heard, respected and included in treatment planning by mental heath professionals, as families often provide the majority of day-to-day care. This is particularly important in relation to discharge planning and ongoing support, and for the one-in-four carers who experience mental illness themselves – whether pre-existing or developing later.

Improved public understanding of mental illness is needed, in order to reduce the isolation and stigma of being a family affected by mental illness. Many family carers also noted that one of the best ways to help them would be to simply improve the mental health care provided to their relative.

In summary

- Families report a range of health, financial and other problems associated with caring for a person with a mental illness.

- Despite a plethora of government carer policies, families remain unsupported and isolated, with very little help for their relative with a mental illness or for themselves. Mental health professionals expect families to provide day-to-day care, but do not give the support or information they need to carry out this role.

- The majority of families struggle alone without help from any carer support organisation. An even greater proportion – almost three-quarters – have never received any education or training on how to care for someone affected by mental illness.

- Families urgently need practical, day-to-day support to ease their role; education and training to make caring work better for their relative and themselves, and respect and inclusion in the treatment team from mental health professionals.

Recommendations

1 PRACTICAL SUPPORT

Families of people with a mental illness receive very little practical, day-to-day support for the enormous caring role they carry out. As well as practical, financial and legal support, respite is needed on a weekly, even daily basis, not just a few times a year as a 'break'. Organisations supporting carers need a substantial increase in funding to provide this help more comprehensively and systematically around the country.

2 MENTAL HEALTH SERVICES

A major contribution to the well-being of family carers would be to improve clinical services for people with a mental illness, as well as the availability of supported accommodation and other community services. This would ease the caring role of families as well as benefit the person with the illness.

3 EDUCATION AND TRAINING

Family interventions based on education and training are among the few treatments – apart from medication – which have proven effectiveness in improving outcomes for people with illnesses such as schizophrenia.*

While there are some education programs for carers provided by community organisations, it is disappointing that nowhere in Australia are the proven family interventions provided as part of standard clinical treatment. Commitment and action are urgently needed by government to make this available systemically at a national level.

4 EDUCATION OF HEALTH PROFESSIONALS

Many health professionals still exclude family carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved.

* Mihalopoulos et al, 2004. Assessing cost-effectiveness in mental health: family interventions for schizophrenia and related conditions. *Australian and New Zealand Journal of Psychiatry* 38 (7), 511–519)

Research Bulletin 6

Physical health care and mental illness

People affected by mental illness experience very high rates of physical illness, yet many do not receive health-checks and preventative advice to deal with this risk . . .

People affected by mental illness have much poorer physical health than the general population, experiencing heart or respiratory disease, circulatory problems, diabetes and other conditions at far higher rates.* Ensuring good physical health care as well as mental health care has long been a challenge.

This SANE Research Bulletin investigates the physical health care received by people with a mental illness, and what needs to be done to improve this.

The survey was conducted during September-October 2007, using a convenience sample of 350 people who completed a questionnaire via the SANE Helpline or website. The majority of respondents were female (74%) and lived in urban areas (63%). They were aged predominantly 25-39 years old, and the most common diagnoses were depression (37%), bipolar disorder (20%), schizophrenia (12%), and anxiety disorders (9%).

What is the state of physical health, and what physical health care is being provided?


10% Mental illness only
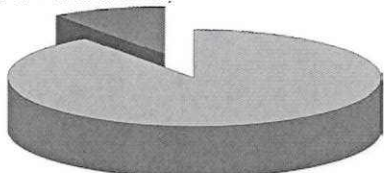
90% Mental and physical illness

As well as a mental illness, almost all respondents (90%) had a chronic physical health problem such as high blood pressure, diabetes, heart or respiratory disease.

The majority (70%) saw a GP for their mental as well as physical health care. Forty-one per cent saw their GP monthly and 35% every six months, with almost all (96%) visiting the same GP or surgery regularly. This continuity of care is important – fostering consistent, informed treatment and a good trusting relationship with the doctor.

What treatment and support are being provided?


55% Exercise discussed
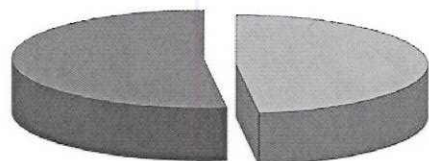
45% Exercise not discussed

Nearly half (45%) had not discussed improving their health through exercise with their doctor, and a similar proportion (43%) had not discussed improving their diet. This is alarming because of the known high rates of diabetes and heart disease among this group.

Nearly all respondents (98%) were being treated with medication, and almost all (93%) were also using some form of complementary medication or therapy, such as St John's Wort. A major concern is that almost half (48%) had not discussed these unprescribed substances with their doctor, as they may interact with medications and have harmful effects.
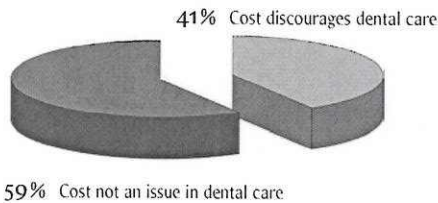

Is physical health being checked effectively?

18% Waist measured
50% Blood tests
52% Smoking check
60% Weight measured
90% Blood pressure taken
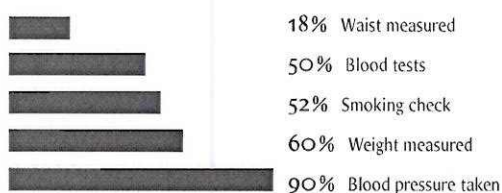
Most respondents (90%) had had their blood pressure measured within the past year, and 60% had had their weight checked.

However, given the high prevalence of diabetes and heart disease among people with a mental illness, the proportion who had received blood tests for cholesterol, sugar levels and liver function was disappointingly low, at just 50%. Only around the same proportion (52%) had had their smoking status checked. Excess waist girth is also a key indicator of serious health problems: only 18% reported that this had been measured by their doctor in the past year.

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Physical health care and mental illness

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R E S E A R C H

Is dental care easy to access?

41% Cost discourages dental care

59% Cost not an issue in dental care

While most respondents had had a dental check-up in the previous year, 41% of them reported that the high cost of dental care discouraged actually seeking treatment.

The importance of oral health can often be overlooked. It has a significant effect on physical and mental health in addition to tooth decay and associated pain -- contributing to secondary infections, digestive problems and social discomfort.

For those on low incomes, however – including the many people with a mental illness on a Disability Pension – the cost of private dental treatment is prohibitive, while public dental care is extremely limited and involves very long waiting times.

In summary

- People affected by mental illness experience much higher rates of physical illness than the general population – 90% of respondents reported having a chronic physical condition.

- Most people affected by mental illness visit the same GP practice regularly, where their physical as well as mental health care is provided. This gives an ideal opportunity to monitor and improve physical health – an opportunity which is often not being acted upon, however.

- Many GPs do not provide basic physical health-checks for their patients with a mental illness, nor do they offer information and advice on promoting a healthier lifestyle – for example, through exercise and diet.

- Dental care is difficult to access for people affected by mental illness, as many of them are on a limited income and public dental services are very limited.

Recommendations

1 GUIDELINES AND MBS ITEM FOR GPS

GP Guidelines and an MBS item for physical health check-ups for people affected by mental illness are urgently needed. These would help ensure that monitoring and promotion of physical health became a standard component of treatment for people affected by mental illness, because of their known increased risk factors.

2 PHYSICAL HEALTH PROMOTION

People affected by mental illness need information and advice from their treating doctors – including psychiatrists – and case managers on how to monitor and improve their physical health. This is especially important with regard to metabolic syndrome: the combination of risk factors for diabetes and coronary heart disease experienced by some people taking antipsychotic medications.

*The high rate of smoking among people with a mental illness (31.8%) is almost double that of the general population, and among people with schizophrenia the rate is around 90%. **
Being such a high risk group for smoking-related diseases means that they should also receive special help to reduce and quit smoking.*

3 COMPLEMENTARY THERAPIES

Use of unprescribed medications and therapies is almost universal among people affected by mental illness. Educational measures are needed to ensure they understand the importance of discussing frankly with their doctor the effects of all medications and substances taken, because of possible toxic interactions with prescribed medications.

4 DENTAL HEALTH CARE

The Rudd Labor Government's commitment to reinstate the Commonwealth Dental Health Program is welcome.

SANE Australia urges the Government to carry out in full the recommendations of the Oral Health Alliance, to ensure that people on a low income – including those affected by mental illness – are able to access affordable, timely, good quality dental treatment.

* Lawrence, D, Holman, D & Jablensky, A. 2001. *Duty to Care: Preventable physical illness in people with mental illness.* University of Western Australia.

** Access Economics, 2007. *Smoking and Mental Illness: Costs. Report for SANE Australia.* Access Economics; SANE Australia.

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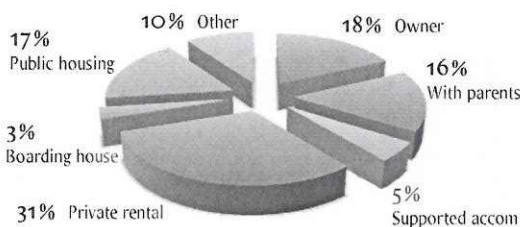
SANE
RESEARCH

Housing and mental illness

*People affected by mental illness are far more likely to become homeless than others –
facing many more barriers – yet do not receive the appropriate help they need to find and retain housing . . .*

Mental illness is acknowledged by the Australian Government as a major risk factor for becoming homeless.* Despite this, a recent study by the Australian Institute for Health and Welfare (AIHW) found that people with a mental illness are 'less likely than other homeless people to receive the type of support they need.' **

This SANE Research Bulletin investigates the housing status of people living with a mental illness, and the factors which help and hinder them from finding suitable housing.

The survey was conducted during March and April 2008, using a convenience sample of 372 people who completed a questionnaire via the SANE Helpline or website. The majority of respondents were female (61%) and predominantly 25-39 years old (40%). Nearly all (89%) had dependent children. The most common diagnoses reported were depression (29%), schizophrenia (25%), bipolar disorder (23%), and anxiety disorders (9%).

Where do people with a mental illness live?

10% Other
18% Owner
17% Public housing
16% With parents
3% Boarding house
5% Supported accom
31% Private rental

The most common form of housing reported was private rental (31%), followed by owner-occupier (18%), public housing (17%), and living with parents (16%). Only 5% were in supported housing.

Nearly half (47%) of all respondents were in unsatisfactory accommodation and looking for somewhere else to live. Almost 90% had applied for public housing but had experienced difficulty with their application.

What barriers do people with a mental illness face in finding suitable accommodation?

People living with mental illness are among the most vulnerable members of the community, living close to or below the poverty line. About 60% of respondents were living on the Disability Support Pension, and 27% were receiving a Newstart allowance.

A key finding of the survey was the extremely high number of respondents (94%) who had been homeless or were without suitable housing at some time. A number of barriers were identified which had contributed to this.

Discrimination
90%
Nearly 90% believed they had been discriminated against at some time, particularly in seeking private rental accommodation – forcing them to accept unsafe or substandard housing options.

Public housing application
90%
Nearly 90% also reported that the complexity of applying for public housing had created difficulties for them.
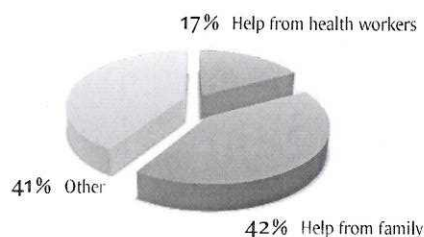
Lack of support
87%
A majority (87%) reported that lack of support around the time they became unwell and were hospitalised had contributed to loss of accommodation.

High rental costs
83%
Eighty-three per cent of respondents reported that high rental costs were a major barrier to finding a suitable place to live.

Housing difficulties also created problems in maintaining relationships with family, friends and heath practitioners, while others needed to cut back on basic necessities such as food and heating to meet rising rental expenses.

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Housing and mental illness

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What helps people with a mental illness to find suitable accommodation?

17% Help from health workers

41% Other

42% Help from family

Fewer than one in five (17%) reported receiving help from a health worker to find somewhere to live. Where people did receive help, the task usually fell to families (42%).

Asked what would help most, almost all (90%) agreed on more active help from health and community workers, and improved availability of low-cost and long-term housing. Many felt there needed to be improvements to the public housing system especially.

Respondents also suggested that help was needed to prevent people from losing their accommodation in the vulnerable period during and after hospitalisation.

In summary

- The majority of respondents reported having been homeless or without suitable accommodation at some time in the past. Many lived with the worry of becoming homeless again.

- A significant number indicated that they had become homeless following a period in hospital, when they had not received sufficient support to maintain their accommodation.

- Many respondents felt they received little help to find suitable accommodation, apart from their own families who were not experts in the area.

- Respondents indicated there was an urgent need to increase the availability and type of low-cost public housing: emergency or crisis, short-term, and long-term supported accommodation.

Recommendations

1   RECOGNITION AS PRIORITY GROUP
The Australian Government's commitment to tackling homelessness is welcome, and the recent Green Paper on this issue acknowledges that people with a mental illness are a primary risk group. * More than acknowledgment is required, however.

The White Paper, due later in 2008, needs to include specific measures to tackle the special challenges faced by people with a mental illness. These should include measures to prevent homelessness, to help this group find and maintain accommodation, and improve availability of housing, including supported accommodation.

2   PREVENTION OF HOMELESSNESS
People with a mental illness need active support to prevent them from losing their homes, especially where they have children. Health services, especially, need to provide effective early treatment, and to ensure that if someone does become unwell and is admitted to hospital, they are not in danger of losing their home.

3   SUPPORT TO FIND HOUSING
Poverty and the disabling effects of mental illness mean that many of those affected have difficulty finding suitable accommodation. Filling out a form to apply for public housing can be a daunting task, apart from the competitive challenge of finding affordable private rental accommodation. More practical support is therefore needed for people with a mental illness to locate and acquire a place to live.

4   IMPROVE AVAILABILITY
With long waiting lists for public housing and competition for scarce private rental accommodation, people with a mental illness are often forced into unsuitable housing or homelessness. It is essential that the range of public housing available be improved, including short-term, emergency, supported, and long-term affordable accommodation.

* Commonwealth of Australia. 2008. *Which Way Home*: A new approach to homelessness. Green Paper. Commonwealth of Australia.

** Australian Institute of Health and Welfare, 2008. *Housing Assistance in Australia*. Australian Institute of Health and Welfare.
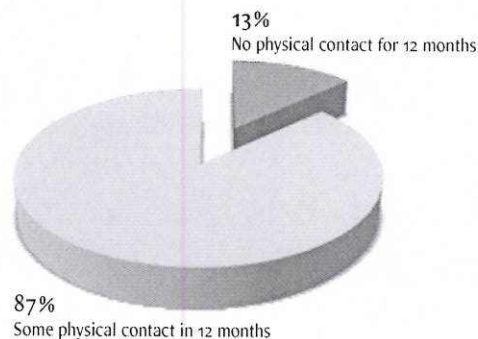
Research Bulletin 8

SANE
RESEARCH

Intimacy and mental illness

The social isolation experienced by people with a mental illness includes a lack of emotional and physical intimacy –
action is needed by government at all levels to improve opportunities for those affected to develop close relationships
with others, and so improve their capacity for recovery.

Social isolation and loneliness are a common experience for many people with a mental illness, especially those who have a psychiatric disability. This not only impedes recovery, it is also a known risk factor for physical and mental health.* This SANE Research Bulletin focuses on the lack of emotional and physical relationships among people living with a mental illness, the consequences of this for their lives, and what can be done about it.

The survey was conducted between September and December 2008, using a convenience sample of 424 people who completed a questionnaire anonymously via the SANE website. The majority of respondents were female (75%) and predominantly 25-39 years old (42%). Nearly all (89%) had dependent children. The most common diagnoses reported were depression (47%), bipolar disorder (20%), anxiety disorders (11%), schizophrenia (10%) and personality disorders (5%).

What is the impact of mental illness on personal relationships?

49%
Not in relationship

51%
In relationship
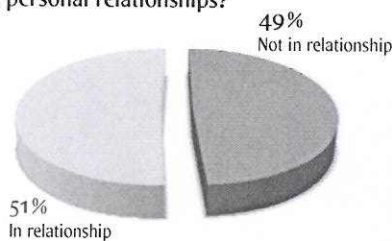
About half of those surveyed (49%) had no close relationship with another person (compared to around 15% of the general population). Almost as many (43%) reported they did not have a close friend with whom they could discuss things.

Being isolated from other people is known to damage mental health. It is even used as a punishment and torture technique in prisons – yet this is a situation many people with a mental illness have to endure, in addition to their symptoms and the poverty they commonly experience.

What is the impact of mental illness on physical intimacy?

13%
No physical contact for 12 months

87%
Some physical contact in 12 months

Almost all respondents reported needing physical intimacy, yet this was rare for many, and a significant number (13%) had not even touched or been touched by another person for over 12 months. Physical intimacy includes hugging and touching others, whether a partner, friend or family member. It is an important aspect of feeling affection and of being valued.
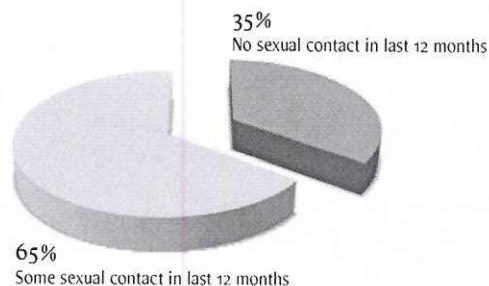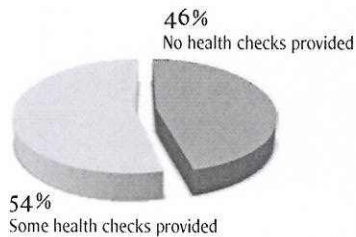
What is the impact of mental illness on sexual intimacy?

35%
No sexual contact in last 12 months

65%
Some sexual contact in last 12 months

Sexual pleasure is a basic human need, as well as being an important part of a loving relationship with another person. People with a mental illness, however, are far less likely to experience sexual intimacy than the general population.** Over one third (35%) of those surveyed reported that they had not had a sexual relationship in the previous 12 months. Sexual desire and function may be affected by the side-effects of medication as well as by symptoms.

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Intimacy and mental illness

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What support is provided for sexual health?

46%
No health checks provided

54%
Some health checks provided

Despite the importance of intimacy in people's lives and the negative impact on it of mental illness, there is little support to overcome this challenge. Half of all respondents reported that they had not discussed the issue with their doctor or health worker, even though many (65%) said that medication affected sexual desire and function. A similar number (65%) reported that they felt they did not know enough about sexual matters, and would welcome support in this important and highly personal area of their lives.

A concerning finding of the survey was that almost half of those who took part (46%) were not receiving regular pap tests, breast screening or checks for prostate cancer. Around one third (32%) had never been tested for STDs. These figures reflect the general poor physical health care provided to people regarded all too often as solely 'mental health patients'.

In summary

❯ Many people with a mental illness lead isolated, lonely lives, often having no partner or even friends to share their lives.

❯ For many people with a mental illness, loneliness is compounded by a lack of physical intimacy – signs of affection such as hugs and kisses. This is a particularly harsh aspect of social exclusion.

❯ People with a mental illness are far less likely to have sexual relationships than the general population, reflecting a more general difficulty in social relations.

❯ People with a mental illness report poor support regarding sexual health, with a high number not receiving regular health checks such as pap smears, breast screening or prostate checks.

Recommendations

1   PROMOTION OF SOCIAL INCLUSION
Action is needed by all levels of government to ensure people with a mental illness are genuinely included in their local communities, and have opportunities to meet and socialise with others. Recovery-focused rehabilitation programs also need to provide support to improve communication and social skills where necessary to facilitate this social inclusion.

2   SUPPORT TO DEVELOP RELATIONSHIPS
Doctors and other health professionals need improved awareness of the effects of mental illness on social relations, and to understand the profound negative impact this has on quality of life and mental health. Education and training is needed in how to discuss the effects of mental illness on emotional, physical and sexual intimacy, and how these issues can be addressed.

3   IMPROVED SEX EDUCATION
The onset of mental illness often occurs in the late teens, disrupting acquisition of life skills as well as education. Health professionals and recovery-focused rehabilitation programs need to provide practical education for people affected by mental illness about sexuality and related issues.

4   SEXUAL HEALTH CHECKS
People with a mental illness, are known to be at greater risk of physical health problems than the general population, yet most do not receive regular health checks. As this survey indicates, checks of sexual health are also sparsely provided.

GPs and health services need encouragement and incentives to provide regular health checks for people with a mental illness. These need to include pap smears, breast screening, prostate checks and testing for sexually-transmitted disease, as well as other routine tests.

* Jablensky, A, et al, 1999. *People Living with a Psychotic Illness: An Australian study, 1997-98 (National Survey of Mental Health and Wellbeing. Report 4)*. Commonwealth of Australia.

Stewart-Brown, S, 1998. Emotional wellbeing and its relation to health. *British Medical Journal*, 17 (7173), p 1608.

SANE Australia, 2005. *SANE Research Bulletin 1: Mental illness and social isolation*. SANE Australia.

** Smith AMA, Rissel CE, Richters J, Grulich AE, de Visser RO, 2003. *Sex in Australia: Summary findings of the Australian Study of Health and Relationships*. La Trobe University.

Research Bulletin 9

SANE RESEARCH

Money and mental illness

Australians with a mental illness struggle to pay for their own healthcare, as well as to make ends meet. Government needs to take a range of targeted measures so that they are able to afford the treatments they need, as well as to participate in the community and improve their quality of life . . .

People living with a mental illness are far more likely to have a lower income than the average Australian, with many relying on the Disability Support Pension. Furthermore, while we are proud of our Medicare system, there are significant additional costs of ill health which it does not cover, and many cannot afford.

Australians face some of the highest co-payment costs for medication in Organisation for Economic Cooperation and Development (OECD) countries, and have out-of-pocket costs close to those faced by Americans.* This SANE Research Bulletin looks at the income levels of people affected by mental illness, the costs associated with their illness, and the impact of poverty on their capacity to look after their own overall health.

The survey was conducted during April and May 2009, using a convenience sample of 371 people who completed a questionnaire anonymously via the SANE website. The most common diagnoses reported were depression (35%), bipolar disorder (26%), and schizophrenia (21%).

What is the income level of people with a mental illness?

31%
Over $50,000

38%
Less than $20,000

17%
$30-50,000

14%
$20-30,000
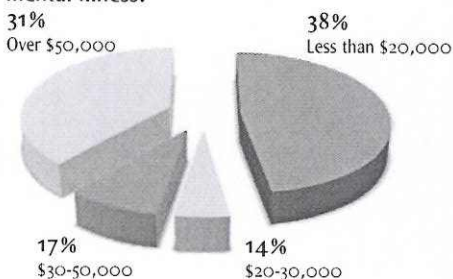
Over a third of those surveyed (38%) had an annual income of less than $20,000, and the majority (54%) lived in rented or public accommodation.

Over half (56%) could not afford private health insurance. A similar proportion (53%) used a credit card to help make ends meet, but many were concerned at the level of debt they were building up.

What are the costs of living with a mental illness?

17%
$100+ monthly on medications

83%
$0-99 monthly on medications
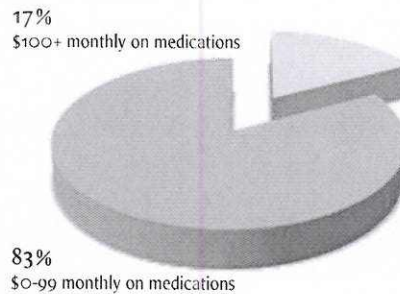
Many costs of having a mental illness are unmet (or only partially met) by Medicare and the social security system. These include co-payments for medications and the cost of over-the-counter medicines; gap payments for medical appointments, plus other recommended health services such as podiatry, dentistry and dietitians.

The majority of people with a mental illness also have chronic physical health conditions (90%) and require a range of medications, as well as having other healthcare needs.** For those on a low income, these costs mount up and can be substantial. One in six (17%) of those surveyed were spending $100 or more a month on medications. Despite this, around a third of those who took part (32%) were not registered with the Medicare Safety Net.

Does cost influence ability to quit smoking?

31%
Smokers

69%
Non-smokers
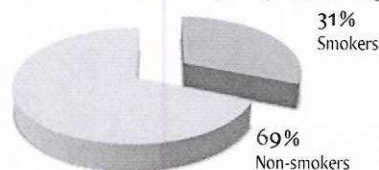
Thirty-one per cent of respondents were smokers, compared to around 18% in the general population, contributing to significant overall health. Nicotine replacement therapy (NRT) is the most effective aid to quitting, yet is not subsidised by the PBS. Almost half of smokers (45%) said that they could not afford NRT, even though they wanted to quit.

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Money and mental illness

SANE RESEARCH

What is the impact of low income on the daily life of people with a mental illness, and on their ability to look after their health?

46%
Able to afford treatments

54%
Unable to afford some treatments
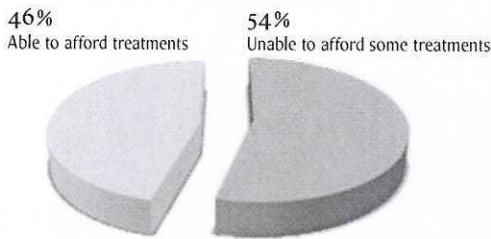
The majority of those surveyed reported that they often had to choose between paying for healthcare or meeting daily needs. Ninety-six per cent said there were times when they were unable to afford essentials such as food. Two-thirds (64%) of those with a credit card were concerned about their level of debt, and, overall, 29% had been contacted by debt collectors in the past year.

Over half of the respondents (54%) said they had not been able to afford treatments recommended by their doctor, and 42% had not filled scripts for medication they had been prescribed because of the expense. A recent study has confirmed that the cost of co-payments does indeed act as a disincentive for people to fill scripts and get the treatment they need, especially if prescribed antidepressants.*** This study also finds that the Pharmaceutical Allowance paid to pensioners has not kept pace with the annual increase in PBS co-payments, and that the Medicare Safety Net threshold is also becoming progressively less generous.

Despite all these challenges, 75% had not seen a financial counsellor for help and advice on managing their money.

In summary

- The majority of people with a mental illness live on below average incomes, with one third surviving on less than $20,000 a year.

- The cost of living with a mental illness is high, with many expenses not fully met by Medicare or social security payments.

- The smoking rate among people with a mental illness is very high, yet they often cannot afford quitting aids such as NRT, which are not subsidised.

- People with a mental illness often have to choose between going without medical treatment or without essentials such as food.

Recommendations

1 FINANCIAL SUPPORT FOR HEALTH CARE
Improved financial support for health care is needed, targeted at making PBS co-payments, gap payments to health professionals, and other recommended medical services affordable for people on low incomes, including those with a mental illness.

2 FINANCIAL SKILLS
Many people living with a mental illness need help with managing money, yet the majority have never seen a financial counsellor. Pro-active steps are needed by government and mental health services to ensure financial literacy and counselling is available for people living with a mental illness.

3 MEDICARE SAFETY NET
One third of people with a mental illness surveyed were not registered with the Medicare Safety Net. The process is too complex and is not automatic. Government needs to ensure all people on low incomes are registered as a matter of course.

4 SUBSIDISED HELP TO QUIT SMOKING
The smoking rate among people with a mental illness is very high, yet many are unable to afford aids to quitting such as NRT. PBS subsidy of such aids is urgently needed, so they can be prescribed to people with a mental illness, pensioners, and others on a low income.

* Hynd, A & Russell, L, 2009. *Recession and depression.* Menzies Centre for Health Policy.

** SANE Australia, 2007. *SANE Research Bulletin 6: Physical health care and mental illness.* SANE Australia.

*** Hynd, A, et al, 2008. The impact of co-payment increases on dispensings of government-subsidised medicines in Australia. *Pharmacoepidemiology and Drug Safety.*

Research Bulletin 10

Stigma, the media and mental illness

While reporting of mental illness in the Australian media is improving, representation of schizophrenia is often inaccurate and distressing to those affected – requiring action to improve community attitudes . . .
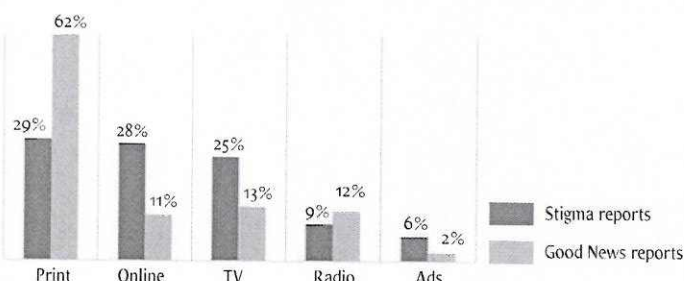
Most people get their information about mental illness from the media. Representation of mental illness in the media therefore plays an important role in determining community understanding and acceptance of those affected. The SANE StigmaWatch program responds to reports from the community about the Australian media, to ensure accurate and respectful representation of mental illness and suicide.

This Research Bulletin examines complaints to StigmaWatch about irresponsible, inaccurate or sensationalised reporting of mental illness ('Stigma reports'), as well as nominations for responsible portrayals that break down stigma and promote improved understanding ('Good News reports').
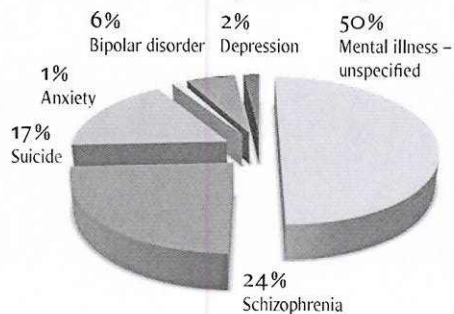
Reports to StigmaWatch from November 2008 to October 2009 were analysed (299), together with the results of a community survey conducted in February 2009 (891 responses), and a series of focus groups on stigma conducted with people affected by mental illness (25 participants).

How do good and poor reporting of mental illness in the media compare?

StigmaWatch reports were spread relatively evenly across major media categories. Good News reports, however, were predominantly from print media (62%) and were often about more considered articles, features and personal stories about living with a mental illness.

What is the focus of StigmaWatch reports?

6% Bipolar disorder
2% Depression
50% Mental illness – unspecified
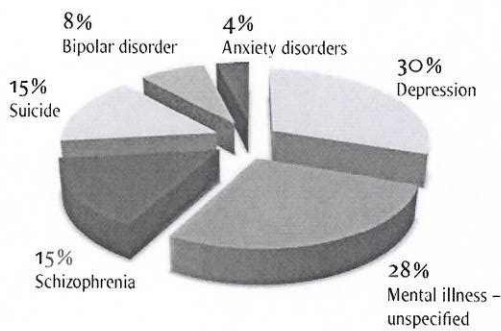1% Anxiety
17% Suicide
24% Schizophrenia

Around a quarter of all complaints (24%) about media reporting of mental illness related to schizophrenia. Many of these articles made an inappropriate association with violence, and promoted the inaccurate stereotype of people with schizophrenia as being always dangerous.

The persistence of such mistaken beliefs was confirmed by the community survey which found that almost 50% of respondents had a poor understanding of schizophrenia and its impact.

A major concern of the focus group participants was also the persistence of false beliefs about schizophrenia. They felt that this stigma 'labelled' them, leading to low self-esteem, loneliness, and isolation from the community. Many also stated that fear of stigma and discrimination was a primary reason for not seeking help, and contributed to denial when they first became unwell. The rarity of media representations of people with schizophrenia successfully managing symptoms and living in the community was identified as a contributor to ongoing stigma and misunderstanding.

	Print	Online	TV	Radio	Ads
Stigma reports	29%	28%	25%	9%	6%
Good News reports	62%	11%	13%	12%	2%

Stigma reports
Good News reports

Stigma, the media and mental illness

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What is the focus of Good News reports?

8% Bipolar disorder
4% Anxiety disorders
15% Suicide
30% Depression
15% Schizophrenia
28% Mental illness – unspecified

Depression was the dominant focus of Good News reports – at 30%, a proportion far higher than schizophrenia (15%) or other diagnoses such as bipolar disorder (8%), or anxiety disorders – which rated only 4% despite being the most common form of mental illness.

Of the few Good News reports about items on schizophrenia, most focused on simply raising awareness of the illness.

Only 10% of these schizophrenia stories acknowledged that treatment enabled most of those affected to live fulfilling, productive lives in the community.

Recommendations

1   STIGMA REDUCTION

SANE *welcomes the Australian Government's commitment in the* National Mental Health Plan 2009-2014 *to 'improve community and service understanding and attitudes through a sustained and comprehensive national stigma reduction strategy'.*

This strategy needs to include a focus on the media, maintaining and building on work already conducted through the Mindframe Strategy.

2   MINDFRAME GUIDELINES

The Mindframe Guidelines *on reporting mental illness and suicide need to be incorporated more consistently into editorial and production processes.*

Ongoing support and research and education work with the media is needed to ensure this happens.

3   POSITIVE PORTRAYALS

More accurate and positive portrayals of people with mental illness by the media are needed if community attitudes are to change. This is especially true with regards to schizophrenia and other less-recognised conditions.

Mental health organisations also need ongoing support and education to facilitate credible, accurate media stories.

In summary

- Different mental illnesses are treated differently by the media. Schizophrenia is often represented in an inaccurate, sensationalised way, promoting an association with violence. Depression is far more likely to be reported responsibly and positively, while other conditions receive little coverage.

- Stigmatising representations in the media have a real and profound effect on people living with a mental illness.

- More accurate, positive representations of people with mental illness in the media will help reduce stigma and discrimination, and promote community understanding and acceptance.

Research Bulletin 11

Suicide, self-harm and mental illness

Having a mental illness is recognised as one of the highest risk factors for suicidal behaviour and self-harm, yet many people do not receive the practical help they need to reduce the risk of further attempts . . .

People living with a mental illness are far more likely to self-harm and attempt to take their own lives than the general population. Suicide is one of the main causes of premature death among people with a mental illness.

This SANE Research Bulletin investigates what practical steps can be taken to reduce suicide and self-harm among people with a mental illness – asking those affected about their experience and what they had found helpful.

The survey was conducted during October and November 2009, using a convenience sample of 285 people who completed a questionnaire anonymously via the SANE website. The most common diagnoses reported were depression (54%) and bipolar disorder (13%). Other diagnoses reported were anxiety disorder (8%), borderline personality disorder (7%), and schizophrenia (6%).

Almost all respondents (93%) had felt suicidal at some time, and 34% had made a serious attempt to end their life during the previous 12 months.

Sixty per cent had deliberately harmed themselves at some time, with 40% of these requiring medical attention. Almost half of those who self-harmed (45%) wanted to end their life at that time.

Are people at risk of suicide recognised as having a mental health problem?

64%
Diagnosis of mental illness

36%
No prior diagnosis
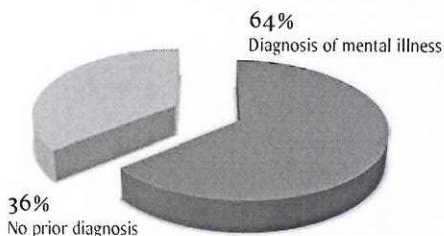
Around two-thirds of respondents reported having a diagnosis of a mental illness prior to any attempt to end their life. The remainder received a diagnosis following an attempt.

Does talking about suicidal feelings help?

27%
Did not talk about suicidal feelings

73%
Talked about suicidal feelings
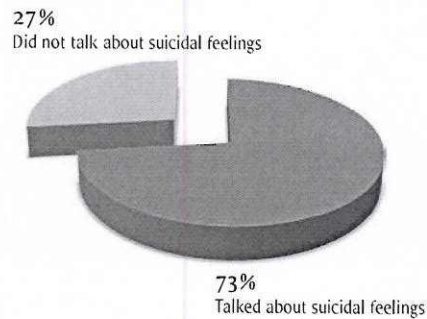
Around three-quarters of respondents (73%) had talked to someone about their suicidal thoughts despite finding it difficult; for most, (59%) this had led to them getting help. This 'reaching out' was clearly an important factor in reducing the risk of people acting on their suicidal thoughts.

People who self-harmed were less likely to talk to someone about it (48%), and when they had, fewer than half of these (40%) were referred for psychological support.

After a suicide attempt, are people given help to reduce the risk of it happening again?

20%
Provided with suicide crisis plan

80%
Not provided with suicide crisis plan
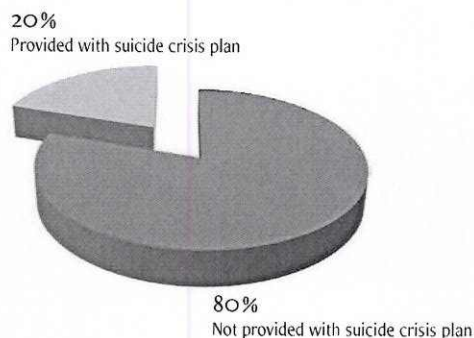
As well as medical attention, most respondents were referred for ongoing mental health treatment after a suicide attempt. However, around one-third (30%) were not. It is also concerning that the majority (80%) were not provided with a crisis plan of what to do if they felt suicidal in the future.

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Suicide, self-harm and mental illness

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Are people provided with psychological therapy after a suicide attempt?

43%
Referred for psychological therapy
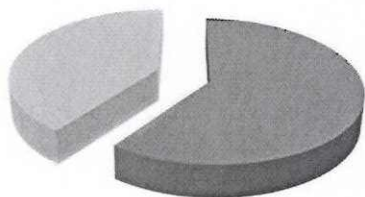
57%
Not referred for psychological therapy

Psychological therapy is a primary treatment for people affected by depression and other mental illnesses. The coping strategies it teaches can play a valuable part in reducing symptoms and stress, and so the risk of suicidal thinking or self-harming. Despite this, the majority reported that it had not been offered to them after a suicide attempt (57%) or self-harm (60%).

What else helps?
Most respondents (57%) had contacted a Helpline when feeling suicidal, and the majority had found this useful (61%). Many (38%) also reported that walking or other physical exercise was a helpful coping strategy. Attending a day program, spending time with friends, and having an occupation (paid or voluntary) were noted as important to improved mental health too.

In summary

- Mental illness is a major risk factor for suicide. The great majority of people who attempt or die by suicide either have a diagnosis of a mental illness, or subsequently receive a diagnosis.

- Talking about suicide can promote help-seeking rather than prompt an attempt. It is important to encourage people to talk about how they feel so that they can receive timely treatment and support.

- Most people with mental illness who attempt suicide receive immediate medical treatment and referral for mental health treatment. Longer-term support is less common, however, and around four out of five are not given a crisis plan of what to do if thoughts of suicide or self-harming return.

- One of the most effective ways of preventing suicide is provision of best-practice, adequately-resourced treatments for mental illness. However, psychological therapy is only offered to a minority of those who self-harm or attempt suicide.

Recommendations

1   RECOGNISING THE RISK
Wider acceptance is needed at a policy and service provision level of the nexus between mental illness and suicide, and the consequences of this for suicide prevention. This is especially relevant to discharge plans, considering the very high suicide rate in the period after someone leaves psychiatric care.

2   REACHING OUT
The Australian Government's Mindframe Strategy has made a valuable contribution to improving media reporting and public discourse on mental illness and suicide. This work needs to continue to educate the community that it is not taboo to talk openly and responsibly about self-harm and suicide – whether concerned about yourself or someone else. This should include simple suggestions on what to do in these situations, and improved awareness of relevant helplines.

3   CRISIS PLANS
An essential part of health professionals' response to self-harm or a suicide attempt should be provision of a simple crisis plan for if the person feels at risk again. This should include basic advice on how to respond and stay safe, a contact number to call, and details of relevant helplines.

4   BEST-PRACTICE TREATMENTS
Best-practice treatments for people who are vulnerable to suicide or self-harm should be a routine part of service delivery – whether in in-patient, out-patient, emergency ward, or primary care settings. This should include psychological therapies to help people manage self-harming or suicidal thoughts.

Response to the pilot Specialist Suicide Prevention Services (SSPS) for GPs has been positive, and the service now needs to be made available nationally, drawing on lessons learned through the pilot program. (The SSPS is provided by the Australian Government through the Better Outcomes in Mental Health Care program.)

Promotion of physical exercise is recommended to reduce stress and depressed mood among people who are vulnerable. Routine provision of rehabilitation, and education about mental illness, suicide and self-harm is also recommended, in order to empower people to help themselves.

Research Bulletin 12

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Social inclusion and mental illness

How well does Australia's social inclusion strategy serve one of our country's most disadvantaged groups? This 'report card' from people living with a mental illness shows there is a long way to go before they are genuinely included in our society, and valued for the contribution they can make . . .

What does 'social inclusion' mean for people living with a mental illness? The term is often misunderstood, but was clearly defined in 2007 by Prime Minister, Julia Gillard:

[Social inclusion means] replacing a welfarist approach to helping the underprivileged with one of investing in them and their communities to bring them into the mainstream market economy. It's a modern and fresh approach that views everyone as a potential wealth creator and invests in their human capital.

Social inclusion is not about Big Welfare, then. It's not simply about increasing spending on social programs. Rather, it seeks to invest in people and empower them – so that they can contribute to and be part of society, rather than be solely recipients of welfare services.

The Australian Government's Social Inclusion Strategy identifies four domains in which this occurs: *Learning*, *Work*, *Engagement*, and *Having a voice*. This Research Bulletin investigates how far people with a mental illness feel 'included' in these areas, and what needs to be done to make social inclusion a reality for them.

The survey was conducted in March-April 2010, using a convenience sample of 559 people who completed an anonymous questionnaire. The most common diagnoses reported were depression (40%), bipolar disorder (22%), anxiety (13%), and schizophrenia (12%).

Social inclusion: Learning

54%
Education cut short

46%
Completed education
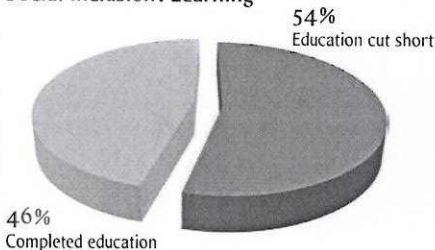
Education is crucial to finding a job and a place in society. Over 50% of respondents to the survey, however, reported that mental illness had cut short their education, and they had not been offered support to continue this later.

Social inclusion: Work

34%
Services helpful

66%
Services unhelpful
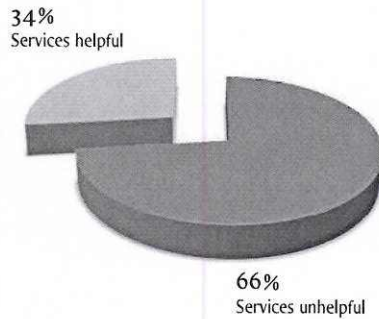
Most respondents (75%) were Centrelink clients. Of these, two-thirds (66%) were dissatisfied with the help provided by Centrelink and the disability employment services to which they referred people.

Centrelink staff often did not understand the impact of mental illness, it was reported. Many employment service staff also had difficulty understanding the needs of clients with mental illness, or had unrealistic expectations of them.

Social inclusion: Engagement

48%
Feel included in local community

52%
Do not feel included in local community
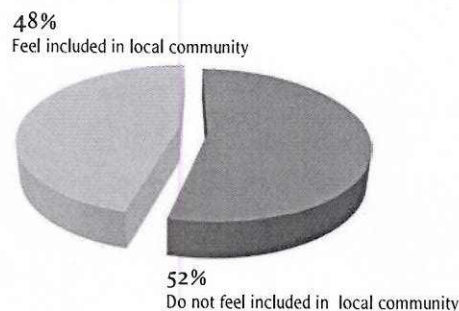
Over half of the respondents (52%) reported that they did not feel part of their local community. Many reported that they had been treated disrespectfully at some time because of their mental illness (42%).

A 'digital divide' was also identified. While 72% of the general population use the Internet from home to engage with others, only 47% of respondents reported being able to do this.

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Social inclusion and mental illness

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Social inclusion: Having a voice

31%
No experience of discrimination
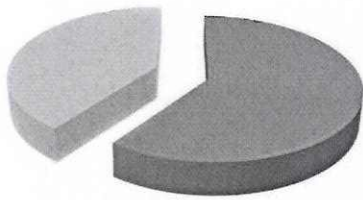
69%
Experience of discrimination

Stigma and discrimination are major barriers to inclusion of people with a mental illness in society – preventing their voice from being heard, and perpetuating lack of action on urgently-needed services.

The majority of respondents (69%) reported experiencing discrimination at some time because they have a mental illness. Despite this, a similar proportion (71%) did not know where to make a complaint, and were unable to name a single human rights agency. Of the few (6%) who did approach a human rights agency, the majority (81%) did not proceed with a complaint as the process was too complex and stressful, or they did not find the agency helpful.

Respondents were also highly concerned that while others groups in society are protected by the law from vilification ('public mockery and contempt'), this protection is unavailable to people with a mental illness or other disability. Nearly all (93%) supported amending discrimination legislation to close this loophole.

In summary

- Many people with a mental illness experience disruption of their education, and receive no support to resume this.

- Centrelink and employment service staff are inadequately supported and trained to help people with a mental illness find work.

- People with a mental illness often feel they are not part of their local community, and are not welcome there. They are also far less likely to be connected to others because of a lack of Internet access.

- Most people with a mental illness do not know where to go for help regarding discrimination, or find the process unhelpful. While other groups in society are protected from vilification (on grounds of religion or culture, for example), this protection is unavailable to people with a disability.

Recommendations

1   SOCIAL INCLUSION: LEARNING
Education is especially important for people who have had studies interrupted by mental illness.

Helping people resume education needs to be made a routine part of treatment and rehabilitation protocols. The Government's Higher Education Participation and Partnership Program *also needs extending to people living with a mental illness, as well as those in low-income families.*

2   SOCIAL INCLUSION: WORK
The Australian Government has made significant changes in recent years aimed at improving access to employment for people with a disability, including mental illness – through the Disability Employment Services and support of innovative projects, for example. Staff at government-funded agencies are often unprepared to help clients with a mental illness however.

Centrelink and employment service staff urgently need resourcing and training to better understand people with a mental illness and how to help them prepare for, find, and be supported in employment.

3   SOCIAL INCLUSION: ENGAGEMENT
Australia has some excellent services to help people with a mental illness engage with their local communities, including rehabilitation programs, the Personal Helpers and Mentors (PHaMs) *programs, and others provided by local councils. Nevertheless, only a minority of people needing these services actually receive them.*

All levels of government need to make a commitment to invest significantly more in these services, so that they become the rule and not the exception.

4   SOCIAL INCLUSION: HAVING A VOICE
The Australian Government's Mindframe Initiative *has made a significant contribution to reducing stigma. Discrimination and prejudice persist in the community, however – not helped by the fact that many people have difficulty finding redress through human rights processes.*

Human rights agencies urgently need to improve promotion of their services to people with a mental illness, as well as the level of support they provide to them. The Disability Discrimination Act also requires amendment to close a loophole which means it is lawful for people with a mental illness (or other disability) to be publicly vilified.

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R E S E A R C H

Parenting and mental illness: the early years

How do Australians with a mental illness fare when they become parents?
How well are they supported during pregnancy and the early years – by maternal and child health services
and by mental health services – and what action is needed to improve care . . ?
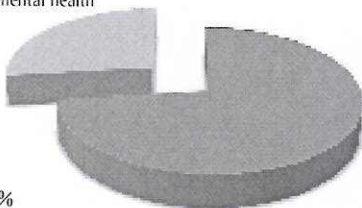
Becoming a parent is a landmark event in anyone's life. Along with the excitement and joy, there are often challenges in the early stages too – including sleepless nights, concerns about breastfeeding and even worries about how well one is going to be as a parent.

All of these concerns are common, and it is a rare parent who doesn't experience at least some of them. For parents with a pre-existing mental illness, however, the challenges can be even greater, as they worry about the impact of their mental illness on the pregnancy and child rearing and vice versa. This study asks these parents about their experience, and what they think would help.

The survey was conducted in October-November 2010, using a convenience sample of 122 people who completed an anonymous questionnaire. Most respondents were female (91%) and aged under 40 (65%). The most common diagnoses reported were depression (52%), bipolar disorder (24%) and schizophrenia (8%).

During pregnancy

44%
Given consistent information

56%
Given conflicting information

During pregnancy, respondents saw doctors and midwives, as well as mental health professionals. Over half of the respondents (56%) reported that they received inconsistent information and advice from these two groups and (52%) also reported being given conflicting advice regarding breastfeeding and medication. This is especially problematic as 58% of respondents felt worried or had difficulties managing mental illness and pregnancy.
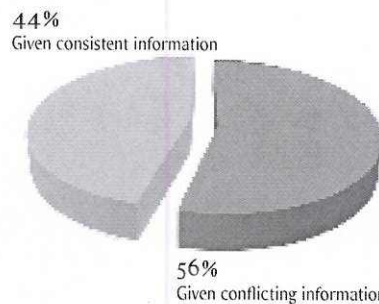
Planning for when you are a parent

27%
Help given to prepare for impact on mental health

73%
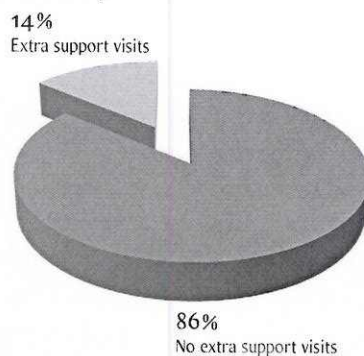No help to prepare for impact on mental health

Not only did the majority of respondents have a diagnosis of a mental illness before becoming pregnant, over half (53%) were also receiving psychiatric treatment. Despite this, most (73%) were offered no support or information on how to plan for the stresses of pregnancy and parenthood on their mental health.

After the baby is born

14%
Extra support visits

86%
No extra support visits

Maternal and child health services can provide additional visits to families needing extra guidance and support. However, the great majority (86%) received no extra support visits at home and only 5% of respondents were provided services such as home help or childcare. This is concerning as half of the respondents (50%) feared losing custody and 22% actively considered relinquishing their baby. Most support during this stressful period had to be provided by partners and grandparents, where they were available.

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The infant years

31%
Aware of support programs
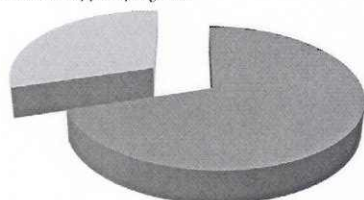
69%
Unaware of support programs

Almost all respondents (93%) felt that mental illness had a negative impact on their parenting to some degree – affecting their ability to relate to and play with their child, for example. While encouragingly almost half (46%) have a care plan, many (38%) reported being reluctant to ask for help and 67% would resist hopitalisation for mental illness, for fear of their child being taken from them.

Programs do exist to help parents in this situation (as well as resources such as *Best for Me and My Baby* produced by COPMI, the Children of Parents with a Mental Illness Initiative), yet almost 70% were unaware of their existence. This indicates a dramatic failure to share information by health professionals, as well as the actual scarcity of such programs on the ground, especially in rural areas.

In summary

- Having a mental illness creates significant additional stresses in addition to the regular demands of pregnancy and parenthood.

- Despite the acknowledged challenge of becoming a parent for someone with a mental illness, health professionals provide little extra preparation or assistance with planning on how to cope.

- People with a mental illness often receive inconsistent information and advice from health professionals concerned with maternal and child health, and mental health. This is not only confusing and worrying, but also potentially dangerous, regarding medication, for example.

- Although extra support and guidance is available for general parenting, as well as practical help for families, these are insufficient for this group, and are poorly promoted where they do exist.

Recommendations

1   IMPROVED INTEGRATION OF SERVICES
Health professionals providing maternal care and mental health care urgently need to work closely together, so that services are coordinated and not focused solely on one area or the other.

2   PLANNING AHEAD
As well as the extra stresses which mental illness places on pregnancy and looking after a child, most parents affected also worry about who would care for their child if they became unwell. Health professionals (especially GPs and case managers) need education, encouragement and support to help parents prepare a contingency plan – if the person does become unwell in the future.

3   CONSISTENT INFORMATION AND ADVICE
Information and advice regarding both pregnancy and breastfeeding, when you have a mental illness, needs to be consistent and evidence-based – regardless of whether supplied by maternal and child health professionals, or by those providing mental health care. Guidelines on this topic need to be developed, widely distributed, and implemented by both groups.

4   PARENTING SUPPORT
In addition to improved access to general and mental health-specific parenting support, better promotion of, and referral to, additional services and resources available for people who need extra support is required.

All health professionals in contact with parents need to be made aware of these services and resources so that they can be provided to people who need them, when they need them – to benefit the whole family.