"Stuck in myself"

isolation and mental health consumers

Mental Health Council
OF TASMANIA

The peak body representing the Tasmanian community managed mental health sector at a state and national level.

I am isolated in this isolation,
There's nobody to hear me,
There's nobody to answer me,
It's just me,
To hear myself scream,
That: 'I am isolated',
Prisoner to this -
Haunting prison,
I am isolated,
Stuck in myself

From the poem Isolation by Ayesha Riaz
Available at http://www.poemhunter.com/poem/isolation-33/

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Tasmanian Government

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Foreword

Darren Carr

With the release of the *Stuck in myself* report, we are both pleased and humbled to highlight the experiences of social isolation experienced by Tasmanians whose lives are affected by mental illness. This has been a significant piece of research for the Mental Health Council of Tasmania over the past 12 months. The process involved interviewing 42 mental health consumers and 20 carers about their experiences of social isolation. Those who heard their stories found them confronting, informative and challenging. At the same time there were times of laughter, amusing anecdotes, hope and resilience. The consumers and carers involved made many recommendations to overcome isolation for others in the same situation.

I would like to congratulate the researchers who saw this project through from conception to publication of this report. Our Policy and Research Officer, Elida Meadows, did a wonderful job designing and leading the research, including all aspects of the ethics approval, reviewing the transcripts and distilling the findings contained herein. Two final year Social Work students, Nina Djekanovic and Sarah Keating conducted many of the interviews over 16 weeks in late 2013. They did a wonderful job establishing strong connections with participants and developing excellent skills that will benefit both themselves and those they work with throughout their careers. I would like to acknowledge the support of Flourish Mental Health Action in Our Hands Inc., Mental Health Carers Tasmania and Carers Tasmania and Red Cross State-wide for their role in helping recruit research participants. Mostly, however, I want to thank and pay tribute to the 62 mental health carers and consumers who gave generously of their time and their hearts by sharing their experiences for the benefit of others. As you read their stories, I hope you are moved to take action to reduce the social isolation so common in the lives of people affected by mental illness

Darren Carr

Darren Carr
Chief Executive Officer

Acknowledgements

This research was funded by a Community Levy Grant. The researchers would like to thank the members of the Project Reference Group, Miranda Ashby / Darren Jiggins (Flourish), Wendy Groot (Mental Health Carers Tasmania) and Susan Sherrin (Red Cross MATES) for their advice on the development of the research and their valuable input into the final report. Tasmania Medicare Local also contributed to the reference group and assisted with data analysis.

The research findings, conclusions and recommendations of this report are those of the Mental Health Council of Tasmania (MHCT). The research for this project was conducted by Elida Meadows, Sarah Keating and Nina Djekanovic. The author of the report is Elida Meadows, Policy and Research Officer (MHCT) who takes responsibility for any errors.

The author would also like to thank Flourish, Mental Health Carers Tasmania and the community service providers who helped us to recruit potential research participants and for providing support for participants during and after the focus group discussions and talking to us about their service. Their support was invaluable, as was the support and input from the staff at MHCT – Sallie Neilson, Catherine Skeggs, Russell Stevens and our CEO Darren Carr.

Finally we would like to thank the 62 research participants who generously trusted us with their stories - their concerns, their fears, their darkest moments and their achievements.

Terminology

All terms, except where indicated otherwise, are drawn from the Queensland Transcultural Mental Health Centre (2006), *Glossary of mental health terms for interpreters and translators*, Brisbane: Queensland Health. This can be downloaded at: http://www.health.qld.gov.au/metrosouthmentalhealth/qtmhc/docs/glossary_mh_terms_v2.pdf

Acute

Recent onset of severe clinical symptoms of mental illness.

Advocate

Person who intercedes for and acts on behalf of a client when the client is unable to do so. An advocate may be a professional or lay person.

Case management/Case co-ordination

The mechanism for ensuring continuity of care across inpatient and community settings, for access to and co-ordination of the range of services necessary to meet the individual and identified needs of a person within and outside the mental health service.

Carer

A carer may be a family member, friend, neighbour, or other community member who provides care and assistance to another person experiencing a mental illness, often in regular and ongoing manner without receiving any recognised benefit or payments beyond a pension or something nominal in some cases.[1] In short, a person with a lived experience of caring for someone with a mental illness or mental health condition.

Community support programs

Social, recreational and rehabilitation programs designed to assist adults with psychosocial disability to meet their needs and develop their potential to live in the community without being unnecessarily isolated or socially excluded.[2] A range of service responses which enable the individual to live as independently as possible and be included in the ordinary life of their community. These are also known as disability support programs.

Community support systems

Resources that are used to bolster the natural support system (including the family) of people living with mental illness in the community.

Consumer

A mental health consumer is a person who is obtaining treatment or support for a mental disorder. The term was coined by people who use mental health services in an attempt to empower those with mental health issues, usually considered a marginalised segment of society. The term suggests that there is a reciprocal contract between those who provide a service and those who use a service and that individuals have a choice in their treatment and that without them there could not exist mental health providers. Today, the word mental health consumer has expanded in the popular usage of consumers themselves to include anyone who has received mental health services in the past, anyone who has a behavioural health diagnosis, or simply anyone who has experienced a mental or behavioural disorder. In short, a person with a lived experience of mental illness or a mental health condition.

Contributing life

A contributing life means a fulfilling life enriched with close connections to family and friends, and experiencing good health and wellbeing to allow those connections to be enjoyed. It means having something to do each day that provides meaning and purpose, whether this is a job, supporting others or volunteering. It means having a home and being free from financial stress and uncertainty.[3]

Mental health

A dynamic process in which a person's physical, cognitive, affective, behavioural and social dimensions interact functionally with one another and with the environment.

Mental illness

Physical, cognitive, affective, behaviouraland social patterns that interact dysfunctionally with the environment.

Natural supports

The personal associations and relationships developed in the community that enhance the quality and security of life for people. These supports typically include family members, extended family members, friends, mentors or community members , and are of a reciprocal (give-and-take) nature. Natural supports can be built up by participating in community activities and projects , joining groups and clubs, volunteering and socialising / interacting with others.[4]

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1. ARAFMI NSW website at http://www.arafmi.org/article/what-carer
2. MHCT definition.
3. National Mental Health Commission (2013), A Contributing Life, the 2013 National Report Card on Mental Health and Suicide Prevention, Sydney: NMHC, p. 14.
4. MHCT definition.

Outreach services

A service that provides visiting specialist mental health services to people who are unable to access such services close to their own community. It includes regular visits from a mental health service located in a major population area, to rural and remote areas and the establishment of formal mechanisms for clinical consultation and support between visits. This is generally provided to rural and remote areas where there are no local mental health services or those areas with satellite mental health services.

Psychosocial

Refers to the interaction between psychological and social/cultural components of disability. The psychological component refers to ways of thinking and processing experiences and perceptions of the world. The social/cultural component refers to societal and cultural limits for behaviour that interact with those psychological differences as well as the stigma that society attaches to [the] label of disabled.[5]

Psychosocial disability

Disability associated with a person's psychosocial experience.[6]

Recovery (personal)

There is no single definition or description of recovery. For the purposes of this report, recovery is defined as 'being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues'.

Recovery-oriented mental health practice

Recovery-oriented mental health practice refers to the application of sets of capabilities that support people to recognise and take responsibility for their own recovery and wellbeing and to define their goals, wishes and aspirations. Recovery-oriented practice encapsulates mental health care that:

- recognises and embraces the possibilities for recovery and wellbeing created by the inherent strength and capacity of all people experiencing mental health issues.
- maximises self-determination and self-management of mental health and wellbeing.
- assists families to understand the challenges and opportunities arising from their family member's experiences.[7]

Self-determination

A person's control of decisions that influence his or her life.

Self-Stigma

Self-stigma is the acceptance of prejudiced perceptions held by others. This can lead to reluctance to seek treatment, excessive reliance on others, social withdrawal, poor self-worth and it may also lead to abuse of alcohol and drugs.

Stigma

A sign of disgrace or shame associated with an illness. Most often involves inaccurate and hurtful representations of people with mental illness as violent, comical or incompetent. This is dehumanising and makes people an object of fear or ridicule. Stigma is considered to be an opinion or judgement held by individuals or society. If these prepositions are acted upon, these actions may be considered to be discriminatory.[8]

Support groups

Groups of people who meet regularly to discuss specific problems that are common to all of them.

Whole-of-Life approach

The International Mental Health Collaborating Network (IMHCN) Charter sets out its mission to achieve a Whole Life for people with mental health issues which is to:

- enable people with mental health issues to obtain full citizenship free from stigma.
- fight for social inclusion in all life domains.
- campaign and advocate for human rights and social justice around the world.
- promote and support community based mental health services through the closure of institutions.
- better meet the needs of the communities through community participation and partnership.
- promote a Whole Life System development approach involving as partners governments, policy makers, community organizations, service providers, professionals, managers, service users and families.[9]

Also includes a whole-of-lifespan approach to mental health – from childhood to old age.

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5. National Mental Health Consumer & Carer Forum (2011), Unravelling Psychosocial Disability: A Position Statement by the National Mental Health Consumer & Carer Forum on Psychosocial Disability Associated with Mental Health Conditions. Canberra: NMHCCF, pp. 6-7.
6. Ibid., p. 7.
7. Australian Health Ministers Advisory Council (2013), A national framework for recovery-oriented mental health services: Policy and theory. Canberra: Commonwealth of Australia; p. 4.
8. Sane Australia website http://www.sane.org/stigmawatch/what-is-stigma
9. International Mental Health Collaborating Network website http://www.imhcn.org/charter

Introduction

The purpose of this qualitative research project is to explore the experiences of social isolation for people living with mental health problems and their carers and to uncover what works for them in terms of achieving social connection and what the barriers to this may be. This research is intended as an exploration of social isolation in people with mental health issues and its impact on wellbeing, recovery and participation in the community. Isolation by people with mental ill health also affects their families and support people and carers have also been included in this project and asked about how this issue impacts on them and their health and wellbeing. The project also sought the views of agencies which currently provide social and recreational supports to consumers.

Social isolation in people with mental health problems has a significant impact on wellbeing, recovery and participation in the community. People with severe mental illness are amongst the most isolated social group of all. They fear rejection from others and may also feel overwhelmed by the thought of attempting to socialise, join group activities, form new friendships, or even, in extreme cases, go out at all. They may also try to conceal their condition from others, resulting in additional stress which can reinforce the impulse to isolate. When people with a mental illness are isolated from social interactions, they become stuck in a cycle reinforcing negative stigmatisation and withdraw from interaction further, reducing likelihood of recovery.[10]

Participants also told us about the importance of peers in their recovery journeys. Peer support groups, being involved in activities with other people with the lived experience and peer workers all contribute to wellbeing and safe social connectedness.

The stories participants told us in the course of this project demonstrate the level of hardship faced by people with mental health issues and their families. However, they also demonstrate the humanity, humour, resilience and capacity for change of people on their recovery journeys.

Executive Summary

This report investigates the experiences of Tasmanians with mental illness that are currently or have in the past isolated, as well as the perspectives of their families and carers. In the pilot surveys for the National Contributing Life Project, people were asked what helped and what hindered them in living a contributing life.

The National Mental Health Commission reports that:

> The three most important things that have emerged from the early findings are:
>
> 1. relationships and connections
> 2. stigma and discrimination
> 3. a sense of personal control, including having enough money[11]

This report corroborates previous research which demonstrates that people with serious mental illness are among the most isolated in the community, and face multiple barriers to participating in the commonplace activities of everyday life.

There can be no doubt from the conversations this study is based on that this cohort experience multiple and at times severe social, economic and personal disadvantages. Apart from their often extreme isolation, the issues they face in their day-to-day lives include:

- Dealing with the symptoms of their illness and often severe side-effects of their medications and the inability to undertake study or work because of these.
- Difficulty in finding and maintaining work due to lack of support and social stigma.
- Finding and maintaining stable housing.
- The poverty related to the majority being dependent on government pensions or benefits as their sole source of income.

On top of this consumers have lower general physical health than the rest of the community and many of them suffer comorbidity in the form of co-occurring mental illness, physical health problems and/or addictions.

We are currently in a climate of budgetary restriction. Government agendas of health reform and welfare reform, both at national and state levels, are driving a push across the country for less welfare spending and restriction of funding for government and community services. At the same time the demand for mental health services is growing. According to the authors of *Crossroads: Rethinking the Australian Mental Health System:*

> …our projections show that if we continue with business as usual, the current mental health system will require at least 8,800 additional mental health professionals, at a cumulative cost of $9 billion to Australia (in today's dollars) over the next fifteen years in order to be able to deliver on this objective. This presents a very significant cost-burden, which in the context of already fast-growing health costs is simply unsustainable. It's clear therefore that Australia urgently needs a 21st century mental health care system to respond to the growing demand for, and rising costs of service delivery. An urgent effort to reconceptualise our mental health system is required, one that looks to better promote and integrate effective and scalable self-help and peer-support interventions, thus decreasing the burden on clinical services and professionals so that they are free to assist those in greatest need. Underpinning this we must prioritise, and fund, mental health promotion and prevention to keep people mentally healthy in the first place. Only then will we experience the health and economic benefits of a 21st century system of mental health care.[12]

Due to lack of services, supported accommodation and programs which can assist them to connect to community, people with severe and persistent mental illness are increasingly reliant on carers, most often parents. This research highlights the high toll taken on carers in terms of their own health and wellbeing.

The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community. The existing services are overwhelmed by the heavy demand they face. Services are often delivered in a piece-meal fashion across the state, leaving many people in regional areas, in particular, without adequate support. Existing programs are also generally unable to provide the level of care and support required to assist a whole-of-life based recovery. The lack of support options means that people with psychosocial disability and their carers are often unable to move beyond the most basic of existences and definitely unable to live a contributing life. More often than not consumers are constantly cycling through the costly acute care sector while their carers develop depression and anxiety disorders.

Funding needs to be provided to ensure that whole-of-person, whole-of-life supports are in place. The mental health sector understands the importance of a comprehensive range of support services in the community. Policies attempt to specifically address the benefits of both clinical and social support in the community to ensure the wellbeing of people with mental illness. However, a commensurate commitment in funding from governments, at both the State and Commonwealth level is lacking.

The MHCT has made a range of recommendations which follow to address some of the more pressing issues surrounding the isolation and social disconnectedness of people with severe mental illness. It has long been established that adequate supported housing is a basic prerequisite for consumers to experience stable and fulfilling lives and realise their hopes for recovery. Our contention is that a successful connection to community is the other basic prerequisite and that people with severe mental illness need to be supported through social and recreational rehabilitation programs to feel safe, confident and connected.

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[10] http://www.mhct.org/documents/MHCTSocialInclusionSubmission.pdf

[11] From the National Mental Health Commission website http://www.mentalhealthcommission.gov.au/our-report-card/ensuring-effective-care,-support-and-treatment/approaches-that-support-recovery,-including-early-intervention.aspx

[12] Aram Hosie, et al (2014), Crossroads: rethinking the Australian mental health system. [Camperdown, New South Wales]: ReachOut.com by Inspire Foundation and EY, downloaded at http://inspire.org.au/wp-content/uploads/2014/03/Crossroads_ReachOut_10Mar2014.pdf

Recommendations

Recommendation 1

Survey mental health consumers and carers every three years

It is critical that consumers and carers continue to be consulted on their quality of life, including social connectedness, participation in their communities and what they need to live a contributing life. A state-wide survey, every three years, along the lines of the National Mental Health Commission's Contributing Life pilot survey can inform the services and programs that consumers and carers require to achieve best outcomes.

Recommendation 2

Whole-of-life approach to mental health programs

It is important that services are based on a whole-of-life approach to recovery, and that they consider all aspects of life, including social support, culture and spirituality, financial, employment, education, housing and accommodation, access to resources, social inclusion, and connection to the community. It is critical that the State Government recognises that social connectedness and participation are essential components of recovery and must be addressed if the goal of keeping people out of hospital and well in the community is to be achieved. We recommend that the State Government directs a proportion of total mental health services expenditure to deliver a range of support, respite and recovery-based services for people with serious mental illness and their carers to be delivered by community mental health organisations. This allocation should be based on need and determined by consultation with consumers, carers and service providers.

Recommendation 3

More psychosocial rehabilitation and community support services

Following on from the previous recommendation, urgent action is needed to implement a systematic state-wide network of recovery-based rehabilitation and community support programs. This network would include an extension of services already provided which are shown to work and new services to meet identified gaps. These programs would need to offer a variety of activities to provide opportunities to help consumers develop social and interpersonal skills, make new friends, reduce isolation, fear and anxiety and form connections in their communities.

There is a need for programs for people with severe psychosocial disability, who may require longer periods of service. Recovery for these consumers may be met by having continued opportunities, with no time limit, for organised social opportunities and activities.

Recommendation 4

Increased resourcing of support groups for both consumers and carers

Research shows that hearing from and sharing with others with similar experiences can be very helpful.

A support group can provide the following gains:

- help consumers and carers understand that they are not alone.
- help members of the group develop new skills in relating to others.
- permit members to 'open up' and discuss their situation and feelings.
- give practical skills and advice – such as how to draw up and stick to a treatment plan.
- provide new coping strategies – sharing solutions and learning from the experience of others.
- offer a safe place to sound off about frustrations of living with a disorder.
- supply strategies for managing any stigma associated with disorders.
- strengthen motivation to stick with a treatment plan.
- help carers learn more about the disorder and become more constructively involved in recovery.

The MHCT calls on the State government to provide resourcing for support groups to be facilitated by consumer and carer organisations and run by peers across the state.

Recommendation 5

Prominent anti-stigma campaign

Renewed efforts are needed to improve understanding of, and attitudes towards, people affected by mental illness. The MHCT and its members strongly support the development of a prominent and sustained social marketing campaign. In order to get coverage and CSA rotation on all major television stations, radio, web and print media; it is important that this project is significantly resourced. It will need to include ongoing evaluation. Social media will be a key element in the campaign and will expand the reach and frequency of the anti-stigma message exponentially. We believe ongoing mental health anti-stigma campaigns should ideally be fully funded by government, as is the case for other public health campaigns such as those targeting smoking and road safety.

Recommendation 6

Training and support for workers in community support programs

Improved training and support is needed for workers in community support programs, so that they are able to provide more effective, evidence based rehabilitation, promote integration with the local community, and to embed the principles of recovery in their practice and service delivery.

Recommendation 7

Improved referral by clinical services

One of the main reasons 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. An investigation into an improved process for the dissemination of accurate and current information on available community support services before discharge from hospital is required to be provided to carers as well as consumers.

Recommendation 8

Resourcing for peer workers to be part of the development and the delivery of recovery-oriented rehabilitation programs

Both government and non-government organisations need to recognise the important role of this emergent peer workforce and invest in quality training in both skill sets and qualifications to best support these job roles. It is further recommended that these peer workers are employed at all levels of the mental health system, in the government and the community, to develop and deliver recovery-oriented rehabilitation programs.

Recommendation 9

Support services for family and other carers

Increased funding needs to be provided for evidence-based support programs for family and other carers to be delivered in all regions of the State. Support programs should include respite and in-home and targeted support for carers of people with psychosocial disability, particularly those who are geographically isolated, socio-economically disadvantaged and from linguistically or culturally diverse backgrounds or other disadvantaged high risk groups.

Section One
Background

1.1 Context

One of the main drivers for this research is the pending roll-out of the National Disability Insurance Scheme (NDIS). The NDIS aims to provide people with disability, including psychosocial disability, the reasonable and necessary supports to live life their way, achieve their goals and participate in social and economic life. It is also intended to fund relief for the caring role — short-term direct respite and social and recreational activities that provide carers with a break from their caring roles. The concern of the MHCT is that programs that currently provide support, including social support to consumers, may be rolled into the NDIS and that the majority of mental health consumers are in danger of losing these supports.

Another major driver for the research is the number of consumers and carers who told us that they were not accessing services or were finding it difficult to find suitable services. This study demonstrates that recovery based rehabilitation programs are critical to the wellbeing of mental health consumers at all stages of mental illness.

There are a number of services offered for consumers and carers in Tasmania and these do a fine job according to the people we interviewed for this study. However, these services are few and far between, especially in regional areas, and are not the systematic network of recovery-based rehabilitation programs that are required to meet needs across the state.

Programs currently available include:

The Aspire Recovery Based Rehabilitation Program is delivered state-wide and is designed to assist people who have experienced a significant mental illness. The program assists participants to make changes that will reduce the impact of the illness and increase opportunities for success and satisfaction in life. The program is intended to teach skills and develop supports and resources that enable people to achieve a role in the community that is meaningful both to them and to the community.

The Australian Red Cross MATES Program is a social connectedness or inclusion program that is run state-wide. The program recruits, trains and supports volunteers to offer ongoing friendship to a person with a diagnosed mental illness. The MATES Program is designed to provide supportive friendships between volunteers and people who have become isolated because of living with mental illness. The friendships not only enhance the quality of life of those involved, but also facilitate community involvement and expansion of social networks by reducing the social isolation faced by many.

Club Haven is operated by Anglicare Tasmania. It is a social and support network for adults (aged 18-60) with mental illnesses who live in Devonport and surrounding areas.

Club Haven provides:

- a relaxed, comfortable, friendly place where Club members can meet, socialise and develop skills;
- a range of activities, such as computer training, First Aid training, cooking, craft or gym, as well as social events; and
- a supportive environment in which to build self-esteem, independence and confidence.

Eureka Clubhouse, managed by Colony 47 in Moonah, is a community based rehabilitation centre run by and for people who have and have had mental health problems. It aims to provide the opportunity for friendship, understanding and confidence in a supportive environment, and at the same time the development of life and employment skills. Participation at Eureka Clubhouse is voluntary with members making the decision about when to attend, how long they attend for and what area they focus on. The basis of Eureka Clubhouse is the work ordered day. The members are involved in meaningful activities such as administration, food services, gardening and maintenance which can lead to supported employment opportunities.

GROW is a state-wide program that operates support groups for people with a mental illness in metropolitan and regional locations. The groups offer a recovery-focused, community-building, educational program based upon a spirit of genuine love, care and understanding. The importance of alleviating the distressing symptoms of mental illness, improving an individual's functioning and enhancing their sense of wellbeing are major priorities of the GROW program. The Program is a cognitive behavioural approach to mental health and is presented in a structured way through weekly two hour meetings with a 12-Step framework at its heart.

Langford Support Services provides youth and adult activity programs for individuals with a mental illness. Programs are conducted from activity centres based in Hobart.

Pathways is delivered by Anglicare in the North of Tasmania and provides structured social activities and skills development for people with persistent and severe mental illness. It is a community program that provides support for day to day living. It provides a friendly, relaxing place for people aged 18 and over with a diagnosed mental illness. Members are a part of a team that plan group activities and outings.

The Personal Helpers and Mentors (PHaMS) Program is funded by the Commonwealth Government and aims to provide increased opportunities for recovery for people aged 16 years and over whose lives are severely affected by mental illness, by helping them to overcome social isolation and increase their connections to the community. People are supported through a recovery focused and strengths based approach that recognises recovery as a personal journey driven by the participant. PHaMS programs are run by Anglicare in the south of the State and Mission in the north.

Richmond Fellowship Tasmania Out & About Southern Recreation Program (Hobart) and the Out & About Northern Recreation Program (Launceston) are recreational programs for people with a diagnosed mental illness. They cater for a broad range of interests and aim to build confidence and increase self-esteem so that participants have the opportunity to access the wider community.

ROPES Inc. (Reaching Out to People in Emotional Stress) is a self-help support group for men and women over 40 who have experienced emotional stress, depression or a mental illness. It aims to provide support from people who have been through similar situations. Meeting twice a week, activities include group discussion, craft, games, relaxation, video/dvd screenings and activities to help build self-esteem. Support is available one-on- one or through group discussion.

In Summary

Despite the good works of the services named above and others, issues remain and they include:

- A fragmented approach to the provision of support programs with no comprehensive system of services across the state.
- Lack of a consistent referral process. Many people only find out about these services by "stumbling" upon them – word of mouth or newspaper articles.
- A definite lack of services in regional areas.[13]
- Insufficient provision of the variety of supports needed to address the whole of person, whole of life span.

1.2 Aims of the research

This research project was designed to explore the understanding of the meaning and impacts of social isolation and social inclusion on the lives of mental health consumers and carers. It aims to identify the challenges to social connectedness, social isolation risk factors and the kinds of programs and initiatives that have supported connection and participation for this group.

In brief the project aims to:

- Ascertain the impact of isolation on the mental health consumer community in Tasmania and its impact on carers and families of people living with mental illness.
- Determine whether the social needs of people with mental illness in Tasmania are currently being adequately addressed.
- Discover the barriers to low levels of participation in psychosocial/social connectedness programs in Tasmania. (There are indications from the research that while psychosocial rehabilitation services can be effective in overcoming loneliness and assisting in management of illness, the majority of consumers and carers are not using them). In particular, is there evidence for low levels of participation because of:
    - A shortage of such services, especially in rural and remote areas.
    - A tendency of clinical services to overlook non-clinical aspects of rehabilitation, such as social support, when assessing and treating clients.
    - The quality of such services.
    - The stigma that surrounds mental illness.
    - Logistical barriers, chiefly lack of transport.
- Establish which programs work and why they work and uncover innovative approaches to social connection.

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[13] There are services that do some outreach and Rural Alive and Well does a good job of delivering suicide prevention, intervention and community wellbeing services to the Central Highlands, Glamorgan Spring Bay and Southern Midlands Municipalities in Tasmania. Rural Alive & Well staff conduct regular farm and house visits making contact with those who traditionally have been isolated or overlooked or are simply doing it tough right now. Rural Alive & Well staff takes the time needed to connect with people, providing ongoing support or referral to other crucial services.

This knowledge will contribute to MHCT policy and community mental health services program development to better address social isolation and promote caring and inclusive communities. This knowledge will also inform systemic advocacy priorities of the peek consumer and carer organisations.

Prior to the commencement of the project MHCT applied for and received ethics approval from the University of Tasmania Social Sciences Human Research Ethics Committee.

1.3 Methodology

1.3.1 Sampling and recruitment

The project recruited 42 consumers and 20 carers who fit the following criteria for participation:

- Current users, or recent ex-users, of social or recreational programs, not limited to those specifically for people with mental illness, who may or may not be currently isolating; or
- Carers of people with mental illness who may or may not be currently isolating;
- Over the age of 18;
- Come from across the state;
- Have the capacity to receive information and consent to participation in the research.

Consumers were largely recruited through community mental health organisations that provide social and recreational programs for people with mental illness and through Flourish, the peak mental health consumer organisation in Tasmania. Carers were for the most part recruited through Mental Health Carers Tasmania and other organisations providing services and support to carers. Some participants joined the study through word of mouth.

Because participants were for the most part recruited from within services that provide social and recreational programs, there was little risk that those unable to consent or participate were included. Before the focus group or individual interview, participants were reminded that if they felt particularly vulnerable or unwell, or susceptible to distress, they were free to withdraw without any further explanation. If during the course of the interview any participant felt uncomfortable and wished to stop the recording or withdraw entirely from participation, they were free to do so. This was made clear on the information sheet and at the start of each interview.

The number of participants recruited was based on information provided by the Mental Health Services Strategic Plan 2006-2011. According to this document, 3% of the Tasmanian population have severe diagnosed mental health disorders (of which 0.6% have the highest support needs) and another 5% of the adult population have moderate to severe diagnosed mental health disorders.[14] This represents 8% of the population which amounts to around 40,000.

Many authors on qualitative research methods agree that saturation is achieved at a comparatively low level[14] and samples generally don't need to be greater than 60 participants with fifteen as the smallest acceptable sample.[16] Other researchers have suggested some kind of guidelines for qualitative sample sizes. Charmaz for example suggests that, "25 (participants are) adequate for smaller projects"[17]; according to Ritchie et al. qualitative samples often "lie under 50"[18]; while Green and Thorogood (2009 [2004], p.120) state that "the experience of most qualitative researchers is that in interview studies little that is 'new' comes out of transcripts after you have interviewed 20 or so people".[19]

The project also interviewed five services providers from the north, northwest and south of the state to ascertain their views of social and recreational services and the importance of these to recovery.

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[14] Tasmanian Mental Health Services (2006), Strategic Plan 2006-2011: Partners towards recovery.

[15] Greg Guest, Arwen Bunce, & Laura Johnson (2006), "How many interviews are enough? An experiment with data saturation and variability". Field Methods, Vol. 18, no. 1, pp. 59-82.

[16] Kathy Charmaz (2006), Constructing grounded theory: A practical guide through qualitative analysis, Thousand Oaks, CA: Sage.

[17] Ibid., p. 114.

[18] Jane Ritchie, Jane Lewis, & Gillian Elam (2003), Designing and selecting samples. In Jane Ritchie & Jane Lewis (Eds.), Qualitative research practice. A guide for social science students and researchers (pp.77-108) Thousand Oaks, CA: Sage, p. 84.

[19] Green, Judith & Thorogood, Nicki (2009 [2004]), Qualitative methods for health research (2nd ed.), Thousand Oaks, CA: Sage, p. 120.

1.3.2 Interviewing

In the first instance service providers MHCT members were approached and given the information about the project to pass on to potential participants. Where practicable, the head researcher visited the service and spoke to the potential participants themselves about the project and answered any questions they had. This approach was tested through an approach to a group of consumers at the Eureka Clubhouse and a group of carers from Hobart Hamlet. Everyone who was present at these information sessions agreed to participate. In cases where it was not possible to visit programs and speak in person to potential participants, the information sheet provided a phone number for contact if there were any questions about the project. People were also offered the opportunity for one-to-one interviews if they would like to participate but preferred this method to focus groups.

Focus groups and one-to-one semi-structured, in-depth interviews were conducted with 42 consumers and 20 carers. Information regarding the research was provided to participants and written consent was obtained prior to the interview. Interviewees were initially approached by the staff of the referring organisations. Interviews were approximately one hour in duration, and were audio recorded and transcribed. All discussions were recorded by a scribe and/or digital recording device, and transcribed. Participants were reimbursed with voucher payments. We also interviewed five service providers to ascertain their ideas about the services they provide.

Primarily, however, the research project was designed to hear the stories of those with the lived experience. This was based on the belief that listening to the experiences of consumers and carers adds depth to the human story of isolation, loneliness and the recovery journey. Obtaining qualitative information also provides depth to systematic empirical investigation of isolation and mental health phenomena via statistical, numerical data.

The interviews were based on a semi-structured approach which is intended to ensure that the same general areas of information are collected from each interviewee. This provides more focus than the conversational approach, but still allows a degree of freedom and adaptability in getting the information from the interviewee in order to remain as open and adaptable as possible to the interviewee's nature and priorities. It is a two-way process where the researcher and participant engage in a dialogue to explore the topic at hand. The questions are an interview guide rather than a formal interview script. This guide outlines the themes and topics to be explored within the interview and includes questions and phrases to prompt discussion. However, these are meant to form a loose guide to the conversation, to allow the participants to explore things that are pertinent to them within the framework of the broader topic. Thus, during the interview the interviewer 'goes with the flow'.

1.3.3 Demographic profile of participants

CONSUMERS:
27 female; 15 male
2 identified as from ATSI community
2 from CALD community

Age Range	Number
18-25	2
26-35	2
36-45	8
46-55	17
56-65	8
66-75	3
>75	2

CARERS:
14 female; 6 male
0 identified as from ATSI community
1 from CALD community

Age Range	Number
18-25	0
26-35	1
36-45	1
46-55	4
56-65	11
66-75	3
>75	0

1.3.4 Project Limitations

The following limitations may have had an influence on the project findings:

- The choice of this research method can result in responses that are more reactive to personalities, moods, and interpersonal dynamics between the interviewer and the interviewee than methods such as surveys.
- Different participants responding to somewhat different questions have resulted in some difficultly in comparing and analysing data.
- The conversational style of interviewing resulted in a few instances of leading questions being asked. (These were filtered during analysis).
- The more subjective style of interviewing can bias results as the evaluator/researcher decides which comments or specific examples to report.
- This research does not attempt to produce measurable indicators of connectedness.
- Discussions about the psychological theories of isolation are beyond the scope of this research project. The research sought to present the experiences of mental health consumers and carers who are experiencing or have experienced social isolation, and it is these experiences that are analysed within the scope of this research.
- Due to the nature of social isolation it is clear that we would not have heard from the most vulnerable consumers and carers.

However, this research method has allowed participants to describe what is meaningful or important to them using their own words rather than being restricted to predetermined categories, allowing participants to feel more comfortable and to be more candid. It has also allowed the interviewers to have the flexibility to use their knowledge, expertise, and interpersonal skills to explore interesting or unexpected ideas or themes raised by participants. Above all, the research recognises the importance and primacy of the voice of the lived experience as both a starting point for further research and as a deepening of the knowledge provided by more empirical research.

Section Two
Isolation and mental health consumers and carers, what are the issues? Literature review

Danielle Elisha and Barbara Hocking (2005) note that social isolation and loneliness are highly prevalent among people with mental illness. They refer to the Commonwealth Department of Health and Ageing report released in 1999 (Jablensky et al 1999) that examined the quality of life of people living with a psychotic illness. The study, based on a sample of 3,800 adult Australians, revealed that 58% of respondents were socially withdrawn, 39% did not have a close friend, and 45% wished they had good friends whilst only 10% of the general population reported feeling lonely. When asked how often they feel lonely, the most common response was "often" (38%), then "all the time" (34%), followed by "sometimes" (20%).

Respondents also reported that having a mental illness has a strong effect on friendship; 85% of respondents felt that mental illness made maintaining close friendships harder and only 8% (21) believed that mental illness led to no change in maintaining friendships. There was a strong perception among respondents that friendship was integral to recovery from the illness, with nearly two out of three respondents 158 (61%) believing that having closer relationships was "very important". Respondents who accessed psychosocial rehabilitation services reported feeling significantly less lonely than those who did not access such services. They also reported managing their illness significantly better than those who did not access such services. Despite the benefits, only 14% of respondents are accessing psychosocial rehabilitation services with any regularity; that is "often" or "very often".

These findings were echoed in a report released by the Mental Health Council of Australia in 2003 (Groom et al, 2003), which detailed the state of mental health services in Australia. The report concluded that: "Mental health consumers continue to experience poor quality of life and tend to remain isolated from the heart of their communities".

Many studies refer to integral aspects of social isolation such as stigma, discrimination, determinants of recovery, feelings of belonging, relationships, unemployment and lack of social support. This review examines the research that has been conducted in these areas in order to ascertain what is already understood about this topic. Particularly, how the research project might add to this knowledge and understanding, specifically within the Tasmanian context.

A review of the literature highlights the fact that social isolation is a multi-faceted concept, including its connection to an individual's physical and mental wellbeing, how it can and should be measured, and its overall impact on communities. Nicholson (2009) defined social isolation as "a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling and quality relationships" (Nicholson, 2009, p. 1346). Social isolation is usually measured by the number, type and duration of contacts between individuals and the wider social environment, an individual's social network.

According to Lloyd Waghorn, Best & Gemmell (2008) people living with mental health problems are among the most marginalised, socially isolated and excluded in society. Carol Harvey and Isa Brophy (2011, p. 74) note that:

> Social isolation experienced by a person with mental illness can be compounded by poverty, language barriers, cultural differences and coexisting health problems. It is important to be cognisant of this complex web of factors and to explore, assess and address them as far as possible. Further, supports to regain social connections should be individually tailored, taking into account the patient's strengths, interests and past experiences. Use should be made of mental health specific services as well as the services available to everyone in the community, according to availability and preference. People with mental health problems are no different to anyone else in finding relationships through a variety of means, such as study, employment and religious or leisure activities. Thinking about recovery in this broad sense is likely to be helpful in supporting people to reconnect socially.

A comprehensive and detailed Australian SANE report, 'People living with psychotic illness' (Morgan, 2010) examined the prevalence and nature of social isolation among people living with a mental illness. The report found that people with psychotic illness are often isolated by the symptoms of their illness and this isolation can be intensified by multiple episodes of illness, periods of hospitalisation and stigma and discrimination that make maintenance of family and social contacts more difficult.

The survey also revealed the ongoing impact of social isolation. One in ten (11.6%) participants said facing stigma and discrimination was one of their top three challenges for the coming year. Almost one half (46.9%) of females reported experiencing stigma or discrimination in the past year, compared with 31.8% of males. Many more (37.2%) reported that loneliness and social isolation was one of their greatest challenges while only 6.2% reported the absence of family or a carer as a challenge. This would imply that what the people surveyed were missing were relationships with peers and social groups and not those with family and carers.

Furthermore, two-thirds (69.3%) of the survey participants said that their illness made it difficult to maintain close relationships,13% had no friends at all, 14.1% had no one they could rely on, and 15.4% had never had a confiding relationship. When participants were asked to describe their involvement in organised activities over the past year, just over two-thirds (68.6%) said they had not attended any social programs, and a similar proportion (69.4%) had not attended any recreational programs. Overall this report found that people living with psychosis ranked social isolation/ loneliness and social/ economic disadvantage above their very profound physical and mental health needs.

In an article in *Medicine Today*, Harvey and Brophy (2011, p. 73) refer to the Australian National Survey of Mental Health and Wellbeing, according to which almost one-third of Australians who have psychotic disorders are living alone and 39% of these people have no 'best friend' with whom they can share thoughts and feelings. They also note that "Although a proportion of people with mental illness withdraw from others as a way of managing symptoms such as paranoia, persistent auditory hallucinations or feelings of depression, poor energy and low self-worth, it is important to recognise that the majority desire more connections with others. In the above survey, 45% of participants felt they needed 'good friends'".

Social isolation and social inclusion

Both social isolation and social inclusion are multi-dimensional concepts. One barrier to social inclusion is self-exclusion by consumers who fear that they don't fit in, will be labelled as "abnormal" or "crazy" or be targeted for abuse and discrimination. The NZ Ministry of Social Development publication, Social Inclusion and Participation: A guide for Policy and Planning identified the key determinants of social inclusion and participation as belonging, inclusion, participation, recognition and legitimacy (Bromell & Hyland, 2007). The evidence is that sharing common experiences, aspirations, values and social attitudes within communities such as sports clubs and religious groups can reduce feelings of isolation and alienation.

A study, 'The role of clubhouse in facilitating social support' found that the clubhouse structure and programs provided exceptional social interaction and comfort for people and a central sustaining means of social support and sense of belonging, which in turn promoted faster recovery from mental health problems (Carolan et al, 2011). This is supported by the study of Borg and Kristiansen (2008) who found that keeping occupied did not necessarily mean being in paid work, but involvement or participation in any activity that was perceived as useful. However, being social and participating is often constrained by the financial barriers that many people with mental health problems face. Several studies have found that in many cases people did not have enough money to join clubs, participate in enjoyable leisure activities or even engage in a lot of 'normal' recreational activities (Granerud & Severinsson, 2006).

Lloyd et al (2008) assert that when we discuss the term social inclusion we are incorporating people's personal journeys of recovery, furthermore social inclusion aims to challenge societal norms and remove barriers for participation in all areas of society. A study by Bradshaw, Armour & Roseborough (2007) undertook a study of 45 people with serious and persistent mental illness. This study was a comprehensive examination of people's recovery over a three year period, culminating in the identification of five essential themes, four of which involved reintegration: into the community; with friends and family; with the case manager; and with oneself. While this study discussed social inclusion, the majority of the findings were presented in terms of reintegration into the community.

Long-term poverty promotes income inequality and material disadvantage through unemployment, financial exploitation and long-term reliance on financial assistance (Bradshaw et al, 2007). Lack of money for transport can limit people's ability to attend appointments, visit friends and family, and to gain and sustain employment (Bradshaw et al, 2007). Following on from the four themes of reintegration identified in the study by Bradshaw et al (2007), the fifth theme tied the previous four together by identifying the barriers to social inclusion. Although all participants reported that they wanted more social connection and inclusion in the community, they struggled to make friends, lacked educational and job opportunities and did not have sufficient financial resources to afford good housing, transportation and leisure activities. The study concluded that despite individuals' best efforts and willingness to reintegrate socially, the community's response to mental illness made it very difficult for them to do so.

Barriers

1. Lack of adequate housing

A significant barrier to social connectedness is the lack of safe, secure, adequate housing. An Australian study by Browne, Hemsley and St. John (2008) focused on the role of mental health professionals as well as the individual aspects of recovery. This two-part Australian study of eight consumers explored the recovery needs, in particular the housing needs, of people following their discharge from hospital. It found that quality, stable housing helped develop social networks and access to resources that support recovery from mental health problems. Financial issues, stigma, discrimination and poor social networks all worked together to restrict a consumer's ability to live where and how he/she chooses.

The "Institutionalisation in the community" section of the Mental Health Council of Australia report *Out of hospital, out of mind!*, gives an example of a common story heard in consultations for this project:

> "My son sits alone in a unit with nothing to do, no motivation, no energy and doped up on a tranquiliser. I see other people like my son around where I live, who appear lost and lifeless, who roam aimlessly all day." (Carer)

Mental health consumers continue to experience poor quality of life and tend to remain isolated from the heart of their communities. In the rare situations where housing is provided, this is often located on the fringe of cities or regional centres, and the difficulties for consumers are compounded by the lack of accessibility to public transport. Several respondents reported that transport difficulties in rural areas greatly impact mental health teams accessing their clients and covering all of their areas. (Groom, Hickey & Davenport, 2003, p. 18).

2. Stigma

There are several studies that incorporate consumers' experiences of mental illness. They highlight the impact that stigma, employment and recovery have on people's daily lives and how these barriers prevent people from being socially included.

An article 'How does stigma affect people with mental illness' by Parle (2012) explains how people with mental health problems face widespread stigma and discrimination, which can diminish self-esteem and deprive people of social opportunities, including employment or accommodation because of their illness (Parle, 2012). Due to these barriers people may therefore prefer to stay at home rather than have an inclusive life.

A study conducted in Western Australia, Reducing the isolation of young adults living with a mental illness in rural Australia (Mostafanejad, 2006), found that isolation was brought about by the social exclusion of participants primarily because they had a mental illness and by behaviour that was associated with this mental illness. This isolation was therefore a result of the lack of knowledge and understanding of what it is like to live with a mental illness by the general population.

In 2004 Kelly and McKenna wrote a paper that discussed the deinstitutionalisation of people with a mental illness during the previous fifty years. The paper looked at whether this process has been the cause of even greater stigma and discrimination as these people are now trans-institutionalised by being "incarcerated" in community houses and flats. The authors go on to say that during the process of deinstitutionalisation, and even now, "the risk that the community might harm mental health patients has been largely ignored" (Kelly and McKenna, 2004, p. 379). There are many unintended consequences of deinstitutionalisation including placing families in the situation where they have to take over the burden of care or the patient ends up living in poverty without employment and suffering from medical and other secondary complications (Kelly and McKenna, 2004, p. 379). The same authors, in an earlier study, suggested that "even when 'asylum the place' has gone, there will always be those patients who need 'asylum the function' (Kelly, L S and McKenna, H P, 1997). The problem with stigmatisation, according to Kelly and McKenna, is that it impacts on consumers' lives in the form of fear of victimisation and this can lead to withdrawal from social activities which impacts negatively on their quality of life (Kelly and McKenna, 1997, p. 383).

The UK has been leading the way by addressing the nature of social exclusion as a primary issue and using their mental health policy to recognise the 'intimate connection between being mentally ill and being poor' (Bland, Renouf & Tullgren 2009, p. 57). In 1998 a five year campaign entitled 'Changing Minds: Every Family in the Land' was started by the UK Royal College of Psychiatrists in an attempt to reduce the stigma of mental illness after many studies had proven that stigmatising attitudes towards people with a mental illness were widespread (Byrne, 1997; Link et al, 1997; & Jorm et al, 1999). In 2000, Crisp, Gelder, Rix, Meltzer and Rowlands (Crisp et al, 2000) conducted research on the stigmatisation of people with mental illness with the aim of gaining baseline data from a large representative sample of the population of Great Britain to guide the campaign to combat stigmatisation.

Through researching the opinions of the British adult population (1737 interviewed; 65% response) regarding seven types of common mental disorders (severe depression, panic attacks, schizophrenia, dementia, eating disorders, alcoholism and drug addiction) they concluded that "negative opinions indiscriminately over emphasise social handicaps that can accompany mental disorders" (2000). These negative opinions, such as perceiving people with schizophrenia to be unpredictable and dangerous, then contribute to difficulties in finding employment, distress and social isolation for those people with a mental illness. Social distancing is then widened by other negative opinions such as perceiving that people with mental illness "are hard to talk to, feel different from the way we do and are unpredictable." (Crisp et al, 2000, p. 6).

A New Zealand study 'Fighting Shadows' by Peterson, Barnes & Duncan (2008) used 11 focus groups to carry out an in-depth investigation of what self-stigma means to people with experience of mental illness. Findings of this research included showing the association between self-stigma and discrimination, and how these two concepts have the potential to impact on low self-esteem and self-doubt. Social withdrawal and isolation was discussed as well as the relationship that self-stigma and discrimination have with social exclusion. Peterson et al (2008) suggested that if empowerment involves wanting to have a positive effect on one's community and having positive self-esteem, then self-stigma can be defined as the opposite of empowerment.

3. Lack of employment

It is evident from previous research that the economic consequences of having an enduring mental health problem are significant (Browne et al, 2008). There is a vast literature that indicates the various benefits of paid employment. A study 'Working on the Edge: The Meaning of Work for People Recovering from Severe Mental Distress in Norway' (Borg & Kristiansen 2008) stated that work is highly valued by most people. It improves health and psychological well-being and has social, economic and political benefits. Furthermore, Borg and Kristiansen (2008) found that work was a crucial part of social inclusion goals in that it was associated with increased self-confidence and self-esteem, raised social status and a sense of belonging. Paid employment can give people financial security and a sense of purpose and belonging which are important determinants of social inclusion (Bromell & Hyland, 2007). Employment provides further opportunities for social interactions and contributes to feelings of self-worth as well as personal status and identity.

A study in 2000 titled 'Mental health and social exclusion among unemployed youth in Scandinavia: A comparative study' by Hammer (Hammer, 2000). followed up with the concept of unemployment as either a result of or a cause of mental illness in young people. Trying to distance this research from the national context Hammer embarked on a comparative study involving different countries with different cultures and different levels of unemployment. Hammer (2000) surveyed nearly 8,000 young people in five Nordic countries (Finland, Iceland, Norway, Sweden and Denmark) using a representative sample of unemployed youth drawn from the national unemployment registers (Hammer 2000, p. 53). The aim of Hammer's study was to investigate what processes led to the social exclusion or social integration of unemployed youth. Hammer found that in all countries, except Norway, social isolation is related to higher level of symptoms of mental illness and mental health symptoms were moderated by high levels of social integration. In Denmark, unemployed youth are in a better financial situation due to a stronger economy and therefore they are better placed to cope with unemployment. They also feel less socially isolated and report fewer mental health problems than unemployed youths in the other countries included in this study (Hammer 2000, p. 53).

Isolation and well-being

Across a broad range of literature, a number of studies have found that social isolation and loneliness can impact seriously on wellbeing and quality of life; including small social networks, infrequent participation in social activities and negative health effects. A study by Cornwell and Waite (2009) indicates that social isolation and loneliness negatively affect both physical and mental health. The effects of social isolation and loneliness have been compared in magnitude to the damaging health effects of smoking cigarettes and other major health risks.

It is widely recognised that having supportive relationships and social networks is essential for mental well-being. The findings of a 2010 survey as part of a research study by the MH Association NSW into friendship, social support, psychological distress and mental wellbeing patterns and trends in NSW, reveal that people with experience of mental illness are often socially isolated with few close friendships, and are increasingly using social media to meet people. Key survey findings indicated that friendships and social support have positive relationships on mental wellbeing and resilience.

Belonging

Hagerty et al, (1992) refer to "one component of connecting one's self into the fabric of surrounding people, places, and things is a sense of belonging. Maslow (1954) identified belonging as a basic human need, ranking it third in his hierarchy." The authors have defined the sense of belonging as the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment. A system can be a relationship or organisation, and an environment can be natural or cultural.

In an account of her experiences as a young woman with a diagnosis of schizophrenia, Sylvia Frumpkin asks, "Is there no place on Earth for me?" (Sheehan, 1982). Psychiatric nurses hear similar statements regularly from clients who are psychotic, depressed, anxious, or suicidal: "I don't fit in anywhere … I feel so unimportant to anyone… I'm not a part of anything."

The impetus for these types of statements has been attributed to a number of psychological concepts, including loneliness, alienation, and hopelessness. However, upon closer examination such statements appear to reflect a unique phenomenon that has received little attention in the mental health literature, that is a sense of belonging. Using a concept- analysis strategy outlined by Walker and Avant (1988), this article presents an analysis of the concept of sense of belonging and describes its potential relevance for psychiatric nursing. (Hagerty et al, 1992, p.172)

This is an area of research that would significantly contribute to an understanding of the sense of loss and inability to "fit in" experienced by many people with mental illness.

Peer support workers in mental health

According to the National Mental Health Consumers and Cares Forum:

> Peer workers are an integral part of implementing recovery approaches for mental health consumers and carers. They have the knowledge and skills to provide support for consumers and carers and a conduit to effective treatments and services. They can support services by providing knowledge and insight about what works best for consumers and carers. Their presence provides a role model for recovery, helps break down stigma and contributes to vastly improved service delivery.[20]

There has been extensive growth in the employment of peer support workers in the United States, Australia and New Zealand over the past decade. It has only been recently, perhaps aided by the promotion of a recovery-focused approach across mental health services, that the value of peer support in statutory services is becoming recognised.

In a longitudinal comparison group study, Min, Whitecraft, Rothband & Salzer (2007) found that consumers involved in a peer support program demonstrated longer community tenure and had significantly less re-hospitalisations over a 3-year period. An Australian evaluation by Lawn, Smith, and Hunter (2008) of a mental health peer support service providing hospital avoidance and early discharge support to consumers of adult mental health services, found that in the first 3 months of operation, more than 300 bed days were saved when peers were employed as supporters for people at this stage of their recovery. What peer support workers appear to be able to do more successfully due to their lived experience is promote hope and belief in the possibility of recovery, empowerment and increased self-esteem, self-efficacy and self-management of difficulties and social inclusion, engagement and increased social networks (Shepherd, Boardman, & Slade, 2008).

Relationships, social networks

The study by Bradshaw et al (2007) indicated that friendship/relationship is considered to be a normal and important aspect of peoples' social lives which can contribute significantly to overall quality of life. It was evident from the data that having a mental health problem impacted not only on the lives of the people with the problem, but also had immediate consequences for the life experiences of their family and friends. The study emphasised how meaningful relationships with family, friends, caregivers and health professionals were vital if people were to recover from mental illness (Bradshaw, et al. 2007).

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[20] National Mental Health Consumer & Carer Forum (2011) Advocacy brief: The peer workforce. Downloaded at e http://www.nmhccf.org.au/documents/MHCA%20CareWF%20Layout%2016-9.pdf
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Carers

There are a number of studies that examine the effect that caring has on carers. Carers and family members of people with mental illness often experience social isolation as a result of stigma or the caregiving burden, which may compound the problems experienced by people with mental illness. Also, relationships within families may break down as a result of the impact of mental illness and lack of information and support. To restore family relationships, patients might require professional assistance to help demystify and explain the impact of mental illness on thoughts, behaviour and mood, and – subsequently – relationships.

At the family or carer level, there are several practical strategies that can be used to reduce social isolation.

- If the patient is living with family, meet with them and assess the extent to which they also are isolated and how they understand what is happening to their loved one. Provide explanations about how mental illness is affecting the patient.
- Assist families in gaining access to information and the support of people such as carer consultants in mental health services in the local area or carer support organisations (e.g. Mental Health Carers Tasmania).
- Arrange respite, which may relieve the burden of caregiving and maintain relationships.
- Refer to programs offering evidence based family interventions, which improve family coping strategies. These programs may be available through mental health services or the nongovernmental sector (Harvey, p 77).

Carolyn C Cannuscioa, *et al* (2004) conducted a study of mid-life and older women to assess the relation between informal care provision and depressive symptoms, taking into account concurrent demands on women's time (including multiple caregiving roles and employment outside the home) as well as participants' access to potentially supportive social ties. This cross-sectional study included women aged 46–71, free from major disease, and examined the interaction between employment outside the home and informal care provision for a disabled or ill spouse or parent.

In all analyses, higher weekly time commitment to informal care for a spouse or parent was associated with increased risk of depressive symptoms. This relationship persisted whether women were not employed outside the home, were employed full-time, or were employed part-time. Higher weekly time commitment to informal care provision was associated with increased risk of depressive symptoms whether women were socially integrated or socially isolated. However, both informal care provision and social ties were potent independent correlates of depressive symptoms. Therefore, women who reported high spousal care time commitment and few social ties experienced a dramatic elevation in depressive symptoms, compared to women with no spousal care responsibilities and many social ties. The same pattern was observed among socially isolated women who cared for their parent(s) many hours per week, but the association was not as strong. In this cross-sectional study, employment status did not seem to confer additional mental health risk or benefit to informal caregivers, while access to extensive social ties was associated with more favourable caregiver health outcomes.

The Who Cares…? Report on the inquiry into better support for carers (House Standing Committee on Family, Community, Housing and Youth, 2009, p. x) notes that:

> Over the years, the shift from institutional care to care in the community has greatly increased reliance on informal care provided by family and friends. In the absence of adequate support, carers are already in crisis. Emerging demographic and social trends are predicted to result in larger numbers of people requiring care and smaller numbers of people able and willing to provide it. Existing pressures on systems of support for carers which have been building over decades are therefore projected to increase. This means that action needs to be taken urgently.
> This is precisely the fear of ageing carers – that when they are no longer able to care for their loved ones, who will provide the support required? Especially when these consumers are isolated, unconnected to the community and with little or no outside support.

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Section Three
What we heard

3.1 Consumers

To protect confidentiality any names mentioned in the comments quoted in this section have been shortened to the first initial.

3.1.1 Isolation

It is clear from the interviews conducted during this project that at one time or other the participants were isolated from the general community. Some of them were still largely isolating and some of them continued to go through periods of isolation. There are many reasons for the social isolation of the research participants. Some of what was told to us paints a very bleak picture of how many mental health consumers live. Many of them described a quality of life which is limited and diminished by their illness and their isolation and a life characterised by extreme loneliness, boredom, financial difficulties, fear and self-stigma. Many had no one to turn to when unwell.

Those who participate in rehabilitation programmes and non-clinical community-based services providing opportunities for social and professional support often discover these programs by accident. There is a shortage of such programs and certainly a deficit of variety with many participants finding, that although helpful, single programs do not generally meet all their needs. However, participation in community support programs does seem to meet at least some of the social needs of people living with mental illness by getting them out of the house and providing them with opportunities to interact with other people. Even with these programs, there remain nonetheless large gaps in helping people to live fulfilled lives. In the absence of programs that can fulfil broader needs and provide a variety of options over a longer period, a number of the participants had established their own informal schedules for each day to get them out of the house and help them feel like they are part of society. One consumer described his normal day:

It makes life very hard, there's still nothing to do during the day. I just wander around cruising around sticking my fingers in parking meters man, sometimes you get gold coins, sometimes you get a handful of coins, other times nothing. That's about it you know, there's nobody really to hang out with … a normal day, go to the gym, session in the gym, after that either here or down to Sally's [Salvation Army] for a cup of tea … that's basically it… I don't drink, I don't smoke … go to church on Sunday and that's about it … apart from that it's just a dead-end thing you know. There has just got to be something better, something to look forward to, there's just nothing to do, that's what there is you know so when you look at that, it's a dead-end scene.

Many consumers told us that they never saw anyone, never went anywhere and would not answer the phone or the door. Mental health consumers have been deinstitutionalised but they are often nevertheless living lives that are locked away; out of sight and out of mind. As one consumer put it:

I call my house my prison even though I know I shouldn't, but when I used to have the house phone connected … most days wouldn't answer it, the door as well, but I am getting better because the people that I do associate with now I consider to be friends and my colleagues and my support group, therefore the world is opening up to me more. But I used to be virtually a prisoner and I was so isolated.

Another consumer describes the sensation of the walls closing in, creating a pressure that led to hospitalisation:

You're here and the four walls are just gradually coming in and you've got just got this little space and then that's when you crack. What I call crack is when you've got to go to hospital and it's like a big dark, black tunnel with no end to it - you can't see an end. They say there is one, but you can't see it. You get so far, but then you slip right back and you slip back further than where you were before and it just takes your energy.

Most of the participants told us that when they were isolating they often spent days without leaving the house. Some of them told us that they preferred to be alone when they were unwell. Another consumer made the point that the experience was different for everyone:

Some people with a mental illness don't understand social isolation because they're very social people, but they have a lot of troubles with mental illness. But the other people will go the very other way and be very socially isolated, so not everyone is the same.

However, even those who indicated that they preferred to be at home and who needed time for themselves, also said that they did sometimes feel lonely and that they know that social connection helps recovery. Typical responses included:

For me it's an internal thing too like it's a feeling of I want to get away from everyone and I need to isolate. I don't want to answer the door and my mental illness is driving me against what's good for me and it pushes me away from everyone that's trying to help and it's the reverse of what I need, but it does, it just drives me back into bed.

I realised that I wanted to go out. I suppose I was getting lonely and at times you realise you really don't have people to phone or hang out with. I also do realise that it's actually mentally and physically good for me to get out because this panic disorder will only get better by interacting.

The majority of those interviewed said that the desire for connection with other people drove them out of isolation "due to the desperate need to not be lonely anymore." They told us that they needed to connect with people because being alone made them "more depressed" or that they are "bored" or that they know that it is "important for good mental health to connect with others." One person pointed out that the impact of isolation was especially felt at Christmas, Mother's Day / Father's Day and other special days.

Feeling alone, depressed, disconnected, despairing of any positive change and unloved can also lead to suicidal ideation and self-harm. We heard that consumers "attempted suicide when left alone." Another consumer told us that:

I spent most of my childhood with other families so I was rarely near my own and then by 12 I was very suicidal. I started getting suicidal at 9 and then by 12 I was so suicidal that I had actually started to push [away] my best friends. I wanted out so I spent a lot of time in that depressed state isolating and trying to think from 12 onwards.

There are times when consumers, like everyone else, need time to themselves whether it is for a short while or during a difficult time of their illness to help them reach more stability. Sometimes, we were told, participants don't want to interact and feel that there are too many activities or commitments. "I do like my home and I like my own space," one person told us, reflecting the sentiments of many other participants.

One consumer reported that she preferred to be on her own when she was going through a difficult struggle with her illness, which she calls a "messy":

I don't actually want people around me in a messy. I don't want them seeing it. I don't want them in it. I don't want their vibe at all.

Others also found isolation preferable in a crisis situation but for personal growth, reflection and "processing, analysing, which you can't do around other people."

Participants told us that other people don't often understand that they do need time alone. Some don't like getting out much, especially as they get older and some said it was just the way they are. It is just part of their "personality" that they need their own space, and are happy on their own. "I am not lonely, but a loner", as one participant put it. For many, being at home equates to feeling safe. One person even told us that, "Going out made things worse."

However, most of the participants felt that, despite some benefits of isolation, there comes a point where it is not healthy and you need the ability to recognise that. There is a need too for appropriate, accessible and safe opportunities for connection in the community.

3.1.2 Relationships and connection

The people interviewed for this study told us that they wanted what everyone else wants when it comes to relationships: feeling like they fit in; social interactions and acceptance; feeling welcomed to come and share; trust; having someone to turn to when they are unwell and someone to talk to who understands and would reach out and care and rally around when things got tough.

One of the saddest things we heard was the statement by one consumer, "I have never loved or been loved." This may be an extreme situation but relationships are not always easy for people living with mental illness, even relationships with family where these exist. In its *2012 Report Card* the National Mental Health Commission noted that the "2007 National Survey of Mental Health and Wellbeing identified that people living with a mental difficulty who had contact with family and friends had comparably better mental health, than those who were socially isolated."[21] Relationships are important in supporting good mental health and in helping people with mental illness to recover. Participants mentioned family as a support - one consumer spoke about the invaluable support provided by his wife, another talked about the role of her husband and her mother in helping her when she is unwell:

… I don't like many people about at all, I like to keep to just my husband there … or other days I get my mum to come up and see me … that's if I'm really bad.

Many of the people who participated in this research do not have family close by and many have lost contact with their families. Some don't have any support from their families and others have minimal contact because they feel that family members don't understand. As one consumer put it, "Family do not always have the skills to deal with someone with a mental illness." Alienation from family can lead to further isolation because of the loss of trust caused by rejection from those who should be supportive whatever the situation. As one consumer put it:

I think I put up barriers to prevent getting hurt anymore and I'm still isolating from my family - haven't seen them for years. They don't seem to want to know me.

Some consumers felt that family members can be unhelpful and "don't know what to do." One consumer said that "Strangers may be preferable in a crisis." One woman referred to the hurt her sister's misunderstanding caused her:

My elder sister doesn't seem to understand and she goes oh, are you alright, are you going to change into someone else? Like she thinks I'm going to turn into a werewolf or something like that. She is 37 and has no insight at all and it really hurts and she tells her friends about it as well. She tells them all these mistakes I've done in the past because of my mental illness and I feel really betrayed by her and you think you can trust family.

Another woman described how her mental illness and subsequent divorce led to alienation from her children:

My living siblings I don't have any contact with at all, they live in a different sort of world to what I live in so I've had no contact with them for four or five years. My children, I don't have any contact with. My oldest son, he lives in Western Australia. We went through a very, very bitter emotional mental divorce and spent five years in the family court fighting for custody or some custody and … I think my children, because they know the old mum, I don't know if they understand the new, well the Mum now and I don't know if they're embarrassed. I don't think their dad speaks very highly of me, he's remarried now, very happily remarried and that made things even worse between me and the children. I have a granddaughter now and I've had access, I've seen her four times, she is four months old so I've seen my daughter four times which is four times more than I saw her last year.

This same consumer talked about how memories of days with the family created sadness today:

Sundays are a really difficult day for me. I find Sundays the hardest day of the week to get through for me … yeah, it used to be such a family day when I was married, it was the end of the week and it was a relaxing day and the whole family was home and getting ready for the start of the week and there was no sports…it was just everybody was at home it was just a chill out day so I just have a lot of memories about families.

Sometimes participants felt that they needed to protect their family members from the details of the situation. One participant said that:

I don't talk to my sons about it either. Actually, I wish I could … it's a bit awkward to talk about … just taking all the experiences I've had and being able to explain to them why these things have happened to me and be more open with them about it.

Many consumers felt that they needed more than family to feel connected, that family alone cannot fulfil the need for connection. One participant expressed this succinctly, saying, "I sometimes get lonely even when living with mum." However, even when they had family support, most participants indicated that it is difficult for them to form and maintain relationships.

Well I find it very hard to join in, I seem outgoing, but I'm not. I find it very hard to mix with people. I never used to be like this, but I find it very hard to get to know people and to mix with people and I find it hard to join any organisations, you know, that would interest me, you know.

One participant referred to the lack of understanding generally, even from church where one might expect more:

I found that society is sort of too close to comfort. They are no help I found, lack of understanding of your experiences with what you're going through. You know the church is like oh I'll say a pray for you, well it's like no, it's not good enough.

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[21] National Mental Health Commission (2012), A Contributing Life, the 2012 National Report Card on Mental Health and Suicide Prevention. Sydney: NMHC, p. 36

Many reported that they had difficulty connecting with “normal” people and that friendships were easier with people with a mental illness. One participant noted, however, that:

Once you start getting out and about, giving out a different vibe, then people come and visit, knock on the door more often, neighbours interact.

Many of the participants have formed friendships through the programs and support groups they attend. Those who have, indicated that friendship helps and that friends pick up on cues when something is not right. According to one response, what is needed to maintain relationships with people with serious mental illness is for “people to persist, to keep loving you and persist.”

3.1.3 Stigma and discrimination

One of the greatest concerns commonly raised by people with mental health difficulties is the stigma that exists in the community about people with mental health issues, particularly those with psychotic disorders. There are unrealistic fears of aggression or “crazy” behaviour, often based on unrealistic media portrayals. According to the 2013 National Mental Health Report[22] discrimination and stigma have “not shifted over the last eight years.” The early findings of the National Mental Health Commission’s own pilot online survey found that 23.3% of respondents said that social discrimination ‘got in the way’ of them feeling connected to family, friends, culture or community.[23]

In its 2013 Report Card[24], the National Mental Health Commission reported that:

We know that such discrimination can play out in the small and daily interactions between people. These micro-inequities, where minor instances of discrimination or inequality are experienced repeatedly, build up to compound a person’s experience of discrimination. These experiences can even be felt coming from those who are supposed to be providing help.

The Commission also notes that 65% of the estimated 3.2 million Australians who have experienced a mental health problem in the past 12 months have not sought help and that stigma may well be one of the main reasons for this.

The majority of participants in the *‘Stuck in Myself’* study mentioned stigma as a major issue that prevents them from participation in the community. They are treated differently, judged and misunderstood as the following responses illustrate:

I think the main thing is the stigma from schizophrenia.

Some young people make it hard for other young people I think because they don’t understand about schizophrenia and they turn them away and stuff.

When you tell someone that you have a mental illness they don’t really know how to respond and you really feel like they’re judging you.

They ran a mile and thought there was “something weird about her” and I couldn’t even put a sentence together to them to explain how I felt so I’ve not seen them and it hurts and other people - I feel like everyone in the street is watching me. And before, I was unable to go into a shop on my own. And it was only when I joined the Women’s Group at Richmond Fellowship that I actually went into a shop. And now I feel comfortable that I can do it on my own.

I was wondering if Centrelink should change the name of [the Disability Support Pension] to something with more energy rather than DSP because when you say Disability Support Pension, well you just see their faces go. And maybe I’ve had bad experiences in the past and stuff, but there’s a lot of stigma about the DSP.

I had this so called friend a few years ago and she was very intelligent and she worked at the hospital … and she didn’t know about me … I would have to go down to ward 1E …she would say … “When you go in you have to keep your back to the wall, you don’t turn your back on them and when there is a full moon they all start howling at the moon,” and I go right.

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[22] Department of Health and Ageing (2013), National Mental Health Report 2013: tracking progress of mental health reform in Australia 1993 – 2011, Canberra: Commonwealth of Australia, p. 7.

[23] National Mental Health Commission (2013), A Contributing Life, the 2013 National Report Card on Mental Health and Suicide Prevention, Sydney: NMHC, p.41.

[24] Ibid.

Furthermore, participants felt that “people won’t employ people with a mental illness or give them a go.” Despite needing a sense of purpose and something to do, there is little motivation to get out of bed. Stigma makes it hard to make social connections or find work.

These kinds of reactions contribute to self-stigma. National and international research shows that discriminatory behaviours compound self-stigma, discouraging people from participating fully in treatment, with negative impacts upon their recovery and health[25] and also in participating in activities. This may also lead to consumers assuming judgement as the following comments demonstrate:

I go to church most Sundays and when I walk through the door and everyone is standing up and singing - I feel like everyone knows straight away about my illness because I’m thinking it.

Self-stigma, yeah I’m really aware of my mental illness and I worry that people can see and know that I got an illness, but they don’t. I just look like an everyday, ordinary person.

Like other members of the community, clinicians are not immune from preconceived ideas about mental illness and mental health consumers. Some participants spoke about the stigma within mental health services and spoke about discrimination by social workers, support workers and clinicians. One consumer talked about a clinician who laughs at her symptoms:

The doctor makes fun of me because I tell him where the voice is coming from and that it’s a famous person and he asks every single appointment that I have – “oh are you still hearing his voice?” And he has this big smile on his face and I feel really uncomfortable and I feel really stupid. He says “do you believe this person is real and he’s there in the room?” and I say yes. But I feel like I’ve got to say no … and I feel like I’ve got to laugh too when he laughs … It’s a catch isn’t it because the medication that you need is good for you so you’ve just got to just sort of grin and bear it. I would like a different doctor but there are so few psychiatrists up here in the north-west.

Due to perceived stigma some consumers are careful to whom they disclose their mental illness and fear telling anyone new in case they are put off any involvement. Some said that they disclose their mental illness only to people they trust. Sometimes, if they are seen attending a program, they will pretend they work there for fear of the stigma:

I really don’t tell many people … Like when I got me haircut this morning and I said I work here you know … I didn’t want them to know that I was a member here you know what I mean?

I make out that I work in the kitchen here helping out mentally ill people; I don’t say that I am.

Others felt that they needed to disclose for various reasons, including in the following examples:

If you meet a woman or you meet a man and you do like them, then you got to be honest and you got to tell them that you’ve got a mental illness.

I let people know I have a mental illness so if something goes wrong, they know what to do.

There are times, however, when people disclose and then regret it, as the following consumer illustrates:

I think it’s helpful to disclose and then I regret telling them because, I don’t know, there are some really nice people at the church that I go to. And one lady I told, she gives me a hug every Sunday now, and asks how I’m going and that and she tried to empathise with me. But I’m constantly thinking I shouldn’t have told her and I worry that she has gone and told other people.

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[25] National Mental Health Commission (2013), A Contributing Life, the 2013 National Report Card on Mental Health and Suicide Prevention, Sydney: NMHC, p.41.

3.1.4 Symptoms and side effects

Connecting to community support and rehabilitation programs can help consumers to build resilience and manage their symptoms. Rachel Merton and Jenna Bateman make the point that:

> While it is clear a reduction in symptoms is necessary for recovery, it has been increasingly recognised that many people need help to build or re-build their ability to function well, as improved functioning does not automatically follow a decrease in symptoms. This can require the support of a number of different kinds of support agencies. Consumers and carers value improved functioning very highly, and one study found that they value this more highly than improvement in symptoms.[26]

It is evident from what participants told us that a number of them withdraw from others as a way of managing symptoms such as paranoia, persistent auditory hallucinations or feelings of depression, poor energy and low self-worth. Nonetheless, the majority of consumers who were interviewed for this study desire more connections with others as noted by one participant, "There can be a deep longing for connection, but you don't have the energy." For those few who said that they preferred to be alone, this desire was often qualified by a stated difficulty with motivation and fear of the outside world which can be actual mental illness symptoms themselves. One participant told us that it:

> *Got to the point where the self-talk and all the stuff coming at me was that I couldn't look in a mirror for about 5 years. Because every time I would come near the mirror, the voices would be screaming "you dirty little ugly" and I couldn't look at myself without this hatred. So I became very isolated for a very long time.*

Without adequate support to help them manage their fears and connections back into the community, despite their symptoms. Many participants found that trying to survive alone increased the severity of the symptoms of their illness, resulting, in many cases, in a cycle of acute episodes and re-hospitalisations.

Symptoms of mental illness can also sometimes turn consumers away from the very people who could help them. One consumer told us that her illness sometimes caused her to feel suspicious of her family:

> *When I become unwell I think that the world is against me, especially my family. I feel I can't trust them even though they are the ones you're meant to trust. I feel isolated and alone from them and they're the ones that help you through the tough times as well.*

Others felt that by being with supportive people they could overcome their symptoms and be able to be out more as the following consumer indicates:

> *My illness is built around personality disorder or complex PTSD and I used to have trouble relating to people sometimes. But also as I say what do I do, where do I go? I'm on my own anyways. When you're with a friend or a partner you can go anywhere, but you walk into places alone and you do still get funny looks.*

The kinds of symptoms participants reported to us included hearing voices, not being able to stop crying, anxiety, paranoia, loss of motivation to maintain personal hygiene and feeling unable to communicate as noted above. One consumer told us that she did not feel able to be out without her dog for very long:

> *I actually get panic attacks after about 3 hours if I'm away for more than that because I want to get back to her [dog]. But if I go with her I'm a lot better. But even then I really want to get back to the house. But you know you need to get out to experience and to make those periods longer.*

Communication can be, but is not always, difficult for people with mental illness. Often their isolation and the symptoms of their illness, even side-effects from medication can cause a loss of the ability to make conventional conversation. Participants mentioned the difficulty of knowing what to say, of making small talk, of understanding the language other people use. As the following two participants put it:

> *One of the barriers that stop people with a mental illness from connecting with their community is not very good communication, not being able to say this is what I want and how can I get [it]?*

> *Yeah, it's language; people don't know how to communicate. I think mental illness is one form or another of communication whether the person doesn't know how to communicate or have the words to communicate.*

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[26] Rachel Merton and Jenna Bateman (2007), Social Inclusion: Its importance to mental health, Mental Health Coordinating Council Mental Health Coordinating Council, Rozelle, NSW, p. 9.

One person undertook a communication course to re-learn the art of conversation:

> *I did a communication course for 20 weeks with teachers and psychologists and really learned how to sit down and have a conversation … and now I can talk to anyone you know, I can have a conversation with anyone … it helped me out, it was good, … It really helped me communicate with everyone and I was in my shell just on me own. Just living in me own world and it really bought me out a bit. I can communicate with most people, everyone really.*

Several people mentioned the need to learn life skills, practical skills, that include how to interact and communicate with other people. Community support and rehabilitation programs helped people to come together in a safe way and practice these skills with mental health consumers and others alike. After being ill and alone for so long, as one person told us, "It's important to learn what other people are like."

Clearly, it is often the symptoms of the illness or side-effects from medication that impede communication. One participant told us that she changes "subjects very quickly when manic, so it is hard for people to keep up."

Many symptoms were directly related to their mental illness but some of these, including slowed responses and loss of motivation can be exacerbated by the medications they are taking and the sometimes drawn out process of getting the medication and the dosage right. As one participant puts it:

> *No one was actually keeping an eye on what I was doing and the medication they were giving me and then when it started not to agree with me, I started having a sort of behavioural attitude difference.*

Participants reported a number of side-effects from their medication including weight gain, loss of motivation, inability to respond verbally to social cues, nausea, and that everyday functioning became difficult. They experienced a lack of energy and were sometimes unable to get out of bed or off the couch, neglecting self-care and housework. Often they were not warned about the side effects of medications. As the following participants put it:

> *When you are on medication, nowhere to go, nothing to do, you fill in the days by sleeping.*

> *… and they keep asking me how I feel and I say to them I'm so tired, I could sleep my life away and I don't want to be like that". Oh no it wouldn't be the medication, this one said, it wouldn't be the medication, the case manager put her six cents in, "it wouldn't be the medication, it's probably your age" and I said "I know people older than me who aren't as tired as I am" and I said "it is the medication, I've been worse since I've been on it."*

> *When I said [to the psychiatrist] one day about this new medication making me tired and my case manager was sitting there and she said "it wouldn't be the medication" and he piped up and said "it's one of the side effects of this medication." And I looked at her and said "see", you know, and I could have hit her.*

If, however, the right medication and correct dosage was given to them, participants found that their quality of life improved. Many talked about medication as a positive thing, telling us that "medication helps", with one participant explaining how a change in medication led to an improved outcome:

> *I stay at home a lot; I don't like getting out that much you know. But just lately, for the last four months, since I've been put on different medication I've been able to get out and socialise a little bit.*

A number of participants talked about agoraphobia which is itself a mental illness involving a fear of being outside. Some participants had comorbidity including co-occurring mental illnesses and addictions as the following two responses demonstrate:

> *The stuff I went through wasn't too good. Psychosis and stuff like that, paranoid and I've got anxiety and depression and I've got an eating disorder. There's a lot to deal with.*

> *But years ago I had no money for Christmas and I hadn't taken my medication. It was about 10 years ago, and I'll use this as an example, and I held up the IGA store … just with a knife and it's something I've never done before and I paid the price. I had to go into prison for a few months.*

Many participants in this study have been diagnosed with more than one disorder; have physical health problems or substance use disorders including alcohol or drug use. Some of them describe the use of drugs and alcohol as self-medication to address the symptoms of the mental illness such as anxiety and depression. They talked about the disconnection of service provision to people with comorbidity, in particular, mental health clinicians not checking or caring about their physical health.

Comorbidity, whether in the form of multiple mental health diagnoses, physical illness and disability or addiction, undoubtedly compound the physical, emotional and financial difficulties faced by people with serious mental illness. At the same time comorbidity exacerbates social disconnection and lack of interaction. The following responses illustrate some of the issues faced by consumers with comorbidity:

I done me knee in and had a knee reconstruction and they were giving me packs of Panadeine Forte. And I got addicted to them and instead of trying to wean me down off them they put me on the methadone. Now I'm on 75 and I'm starting to come down. Yeah and I'll tell you what, you get that stigma, that drug use and all that.

Well I got a physical disability, I got an intellectual disability, I got a mental illness and all the problems as well my other issues.

Participants talked about how depression and anxiety has led them to self-medicate on drugs or alcohol or both. Staying home alone and needing an escape was another thing that led to alcohol or substance abuse. The help they needed to deal with substance abuse was available but we were told of long waiting lists for drug rehab programs. In the meantime, the consequences of addiction intensified. One person spoke about ending up in prison after a psychotic episode brought on by taking crystal meth.

3.1.5 Finances, home, employment

Financial constraints generally mean that consumers are often not able to afford to participate in activities. In particular, they are unable to participate in those activities which are not subsidised, which are usually more mainstream activities or are natural supports in the community like sports clubs or volunteering opportunities. One consumer referred to a community art course which, "costs $35 and then you still have to pay for art supplies." This inability to afford to participate in general activities results in continuing marginalisation of people with mental health issues.

One of the biggest barriers to participation is access to transport. Not many consumers can afford to own or run a car and other transport options are often unavailable, unaffordable, and this results in an exacerbation of social isolation. Without adequate transport the participants in this research were unable to access services or to maintain contact with family and friends. Other issues included social phobia associated with public transport use and physical conditions that make it difficult to get around.

Aspire - I used to be a member of that. I stopped going because I didn't have the transport to get there.

Transport is a big issue if you don't have it. I caught a bus once and I had a major panic attack, I thought I was having a heart attack.

Yeah it's a big issue … I've got a cyst on the hip and I have trouble moving my hips and walking a lot - I used to love walking, but I can't walk a lot anymore I get sore calf muscles and stuff like that.

For some people, desperation can lead to desperate acts, as illustrated previously. Generally, lack of money means that most consumers have to consider very carefully how they spend their money.

I don't have money basically … this is a private rental, highly expensive … [and] I have a pharmacy account, I have the hydro, the car is not registered. I don't have any spare money at all … Like going for a coffee you know, you're looking at five dollars for coffee and that's two loaves of bread. And I've never ever, ever been in a financial situation where I've had to worry about where I am going to get the money for a carton of milk. I didn't even know how much a carton of milk was until two years ago and I had to go in and buy one.

Financial difficulties can also contribute to homelessness. Two participants referred to homelessness and the alienation it can cause:

Yeah, ostracised, homelessness. Not inclusion eh? Exclusion.

Being homeless - makes it hard to relate to people.

People living with mental illness often live in a cycle of inappropriate or unacceptable forms of accommodation including hostels, boarding houses, caravan parks, "sofa surfing" with various friends and acquaintances, or living rough on the streets. Accessing and maintaining appropriate, safe and secure housing is a big issue for people with mental health issues due to reasons including poverty, discrimination and stigma, difficulties with managing finances and incapacity to maintain housing due to illness. Often, where there is family, they become the fall-back position which is not always the best outcome for the consumer or the carer.

3.1.6 Peers and peer support

It was generally accepted, as one consumer put it, that "People without a mental illness do not always know how to handle someone with mental illness." The importance of peers to mental health consumers is of overwhelming importance to nearly all those interviewed, one consumer declaring that, "peer support is vital otherwise you may stay 'stuck'".

Peer support includes having peers involved in service provision as well as the importance of peer support groups. Many consumers, including the following, told us that they could only fully trust people who had the lived experience. The following comments illustrate what connecting with peers means to consumers:

I think they [general public] don't understand so you make a whole new support group, whole new network of people and that is the thing that has helped me the most because these people do know what they're talking about and everyone has virtually been in the same boat in one form or another and so we all try and support each other, so yeah it's good.

Empathy radiates differently than experience- you just read each other … somehow when a person with a mental illness talks to another person with a mental illness, whether recovered, half recovered, as long as they're not too delusional … you're basically side by side and you do the dance.

It did open a new world with liked-minded people, I met people who liked me for me and didn't care if I was a bit off one day. Yeah and then things just snow-balled and doors were opening and now I can't keep up with everything … it's important that you guys have all these years of wisdom that you bring to that group … wisdom from lived experience and that actually sometimes you don't need a person with a degree and its actually you guys that have being running this successful group

Many participants told us that it is an inspiration to have role models who have been through similar experiences. Working as a consumer consultant is one pathway for consumers who want to work in the sector. There is currently a peer workforce and a Certificate IV in Peer Work about to be rolled out to train more consumers and carers to work as peer consultants and support workers both in the government and NGO sectors. One consumer support worker talks about the positive outcomes for her of this work:

I heard a wonderful talk, there's a lady called Fay Jackson, she's from the mainland and she has, well she has bipolar … she goes around doing talks to people to help them to understand and the story she tells about when she is manic, when you leave the show you not sure whether you just been to see a stand-up comedian … She is great to listen to and she is really honest.

I was approached to facilitate 'Hearing Voices' and that was three years ago and now I am a consumer support worker. So Richmond Fellowship has assisted and helped me in my life and my recovery and I work with wonderful people and I just love everyone in the group. So I consider all these guys as my friends and I feel blessed that I've got people around me that respect me and just like me for who I am.

Peer support groups clearly made a big difference to the lives of many consumers interviewed for this project.

Those specifically mentioned included:
- Al-anon and Al-anon family groups: good way to discuss issues.
- Project Bloke – for men who have had mental health issues to support each other, have coffee, discuss how you are feeling.
- The 'Hearing Voices' support groups come in because you learn to accept the reality of our experiences and our voices are real.

In the end, peer support groups were described as working because:

We have a comradeship in the group and we all care about each other and it is genuine
It's really important to have that safe place and to be able to talk to someone about things that you can't necessarily talk to your GP with.
We're not completely mad after all.
There is stuff that I wouldn't dare tell my family over things that divulge in this group and where I wouldn't share them anywhere else and I think that's really important to have your support network where you can sort have say oh look, I feel really bad today this voice is telling me to do something.

One person who lives in a regional area told us about how seeing a PHaMS worker once a fortnight helped her to re-connect with her music and led to recordings and performance and a renewed sense of self. The final word has to go to the consumer told us that:

If anyone took these groups away there would be a spike in suicides, problems for carers, separations.

3.1.7 Programs and activities – what works?

The consumers interviewed for this study named many programs and services currently available as having made a difference to their lives. In particular they mentioned the Eureka Clubhouse, Red Cross MATES, Club Haven, Flourish, Grow, Pathways, PHaMS and Aspire. There were a large number of positive comments about all of these programs, many of them claiming that an individual program saved their lives or, at the very least put them on the pathway to increased participation and satisfaction with life.

A typical comment was:

Well you know what started me off on the right track, it was definitely Red Cross Mates. If I didn't have them then I probably wouldn't be here now, that made a big difference to me.

However, each of these programs on its own does not satisfy all of the social / rehabilitation needs of most consumers. Typical responses were:

This is about the only time that I come out all week, … on Wednesday to work in the kitchen at Eureka. I'm desperate for something else to do.

Eureka won't lead to everything that I need, it's not enough.

The kinds of benefits that these programs provide are variously described by the majority of consumers interviewed as:
- Meeting social needs.
- Programs with a structure help you to get regular functioning, get out of bad night life habits.
- Provide a safe space, free from stress/paranoia/stigma/judgement/abuse: relaxed place, no noise, no stress, no violence, no arguments, everyone treated with respect.
- Provide activities, helping with boredom and the need for something to do.
- "People notice me - I feel invisible everywhere else."
- Has helped recovery.
- It's free.
- Involvement in courses and basic living skills like cooking.
- Training in computer and other basic skills is helpful.
- Outings with people they can trust and feel comfortable with gets people out of the house.
- Learning tools to deal with symptoms including mindfulness and other courses which calm anxiety.
- Being in a friendly, comfortable place boosts confidence and self esteem.
- It feels like a community.

Many participants spoke about other activities outside of programs that helped them make connections. Some people are able to successfully get involved with activities in the community that are not specifically intended for people with mental illness but for anyone who is interested. It was apparent from what we heard that for some consumers the chance to interact with people outside of the mental health sector in a safe and respectful way made a lot of difference to their confidence. One consumer told us, "I enjoy the help of the students who come to Eureka on placements but miss them when they leave after a short time."

One consumer talked about dog walking as a way to meet people and make friends:

My main thing is obviously my dog. It's the only way I really get to meet people- other dog walkers otherwise you don't meet people … Dog walkers become friends that's where I've met most people, otherwise if it wasn't for her (dog) wouldn't of have met anybody here.

Religion and church were mentioned by several participants as a way to be connected in the community. One participant enjoyed UCB Christian radio and another found that reading the Bible helped when she was struggling. Some felt that church is good for meeting lots of different people and one consumer didn't go out much at all but went to church. However, this was also described as an activity that could not fulfil all a consumer's needs, as one participant put it:

Church is [about] social inclusion, but I must admit they've got a really quite old congregation there …. I just can't click with them, they are lovely people but I just can't go bush walking with them, but conversations are good.

Like everyone else consumers enjoy activities like attending football matches, listening to music and many participants talked about volunteering. One person talked about music and song writing and another mentioned writing and poetry. Others talked about the therapeutic benefits of having pets which were viewed as undemanding, safe and companionable as described in the following quote:

…because I don't hear their voices, I have an incredible relationship and dialogue with animals but not so much human beings because they [animals] can't damage.

Some participants mentioned the importance of good clinical support, particularly the importance of having a really good GP and a really good psychiatrist. Others said that they would like clinical support provided for people attending rehabilitation programs as the two following comments demonstrate:

Eureka really helped recovery, but need to provide more clinical support and addiction support services.

It would be helpful to have a psychiatrist or psychologist come in once a week or once a fortnight for some one-on-one appointments

Many of the participants referred to the need for and importance of education and training to help them "think about the future and what you are capable of" and to support entrance into the workforce. They welcomed programs that provided this kind of support.

Finally, many of the participants spoke about the benefits and the desire for reciprocity - wanting to give back to the community. "I feel better being able to contribute to something," one person told us. Participation, volunteering and helping others is empowering and gives consumers a reason to get out of their homes and can get you out of isolation.

3.1.8 What doesn’t work?

It is clear that there are not enough community support programs, and that many consumers feel abandoned to their isolation and at the mercy of their illness. There are good programs available but they are not resourced enough to provide the support needed across the state. One participant referred to a program that he perceived as working very well but it is only offered in the north-west:

I like Club Haven; we want something like that in Launceston. We need it, we need something because there is nothing available.

The overwhelming message we got was that consumers wanted a genuine, caring, empathic, positive and understanding response to their mental illness and the situation they are in. In particular, there is a general perception amongst consumers that many clinical and government services are impersonal, ineffectual and dehumanising. Typical responses were:

Yeah when you rely on governmental departments which are so impersonal and ineffectual, you know, a few times I’ve dealt with say Centrelink. … That’s so annoying and dehumanising. They cut you off even if it’s their mistake so it’s a frustrating voiceless kind of world.

… It’s a case of she is going home, there is another bed. They don’t think about when she goes home and what happens then. It’s all about there are beds free and I’ve got a patient in DPM that needs to come up. It’s like you’re a number.

I started to think about things like they send you home from the ward with nothing and the GP doesn’t give you much and the only thing you’re always given is Lifeline - poor old Lifeline number.

Consumers often feel that they are being treated without due care and consultation, claiming a lack of continuity of psychiatric care, a lack of handover and a lack of consideration of their concerns. They mentioned problems with clinical support; doing the rounds of different doctors; being used as “a lab rat with lots of different meds.” They talked about the lack of outreach services and afterhours services. One participant talked about the dearth of therapeutic programs like group therapy which, “keeps you motivated and gives structure, you interact with others.” Others said that they are not consulted and their questions are not answered. One consumer talked about how she overdosed in order to receive the support she needed:

One point I would like to make is that people should not have to want to overdose deliberately - and I have done it - to get into mental health services and get included into the mental health system … only number I really knew was Lifeline … it shouldn’t have to come to that and people should be followed up on after being discharged from the hospital, … when you get out what do you do? You said about Eureka, that’s about it isn’t it? There isn’t anything, say in Kingston, is there which is something I could attend?

Help lines and support organisations were described as not always being very helpful.

These associations say we’ll help you just ring us up and you go and ring them up and there is no one there. Well what are you to think to yourself? Well they’re not there so what’s use … you’re crying out for help, but there is no help out there for you so what’s the use of being on earth? … You’re crying out for help and there is no one there and there is no one else you can ring up and say I want to talk. Sometimes that’s all you might want, it may only take someone to talk to you and listen to you … Having someone that you know cares for you and is willing to talk and listen to you helps you more than the medication sometimes.

For some participants, the idea of mixing only with other mental health consumers was not helpful. Some felt that they did not want to be around people with ‘worse’ mental health problems and that not all people with mental illness are the same. And not all of them are interested in social activities on offer – “bingo, dinner, bowls.” One consumer told us that:

As good as I think a lot of the programs are, I think that if you get involved with a group where everybody has a mental illness then you don’t connect with people who don’t. And then you become very secular you know, that’s all you hang around with.

Participants in one program which has recently changed told us that they would like to go back to how the program was before. This program cut some social activities and consumers were told that they were becoming too dependent on the service. They were “not allowed to come here anymore and have lunch and sit around and play cards and games.” Participants in this program said they missed the lunches they used to have there - “It was safe. You could decide what you wanted to cook and other people would join in.” Although there were previous frustrations with the program, participants were unhappy with the changes which involved more prescribed activities “chosen for them” and less social activities. This has led to many of them being no longer in contact with the friends they had made there.

Consumers from remote areas spoke about the lack of services and the increased fear of stigma from living in a small community:

I can only speak from out in Longford, Perth - there isn’t anything out there for mental health people.

See the thing is in small places like these … you see I started a Grow Group in Oatlands … because that was something positive that I got out of hospital. Every week they’d have Grow and I started a group up and the first couple of meetings [were] good and then people just didn’t want to go because when you live in a place like this I think they think all the people are going to judge me if I go.

3.1.9 Trauma

A trauma history can contribute to feelings of low self-worth, distrust of other people and a tendency to isolate. Participants reported that they were bullied, had suffered sexual and physical abuse and were traumatised by mental health interventions. The following are typical of responses received:

I’ve also been sort of sexual molested on a school bus in front of 50 kids for 4 years. Um and then there was like ongoing trauma like my birthday like my 16th birthday and yeah that didn’t like get bothered with at all.

… potentially get more trauma from having to retell somebody new who will automatically, like everyone new, want to put me on different medications.

I think I had problems growing up, I had something happen to me when I was 5 years old and…. I was raped, but very very bad that I had to have my anatomy reconstructed.

I’ve been in hospital that many times that I don’t even know where I was any more I couldn’t even give you a number. But the thing is I’m doing really well now and I made a mistake with one of my tablets otherwise I wouldn’t have gone in. But I want to keep out of hospital. It’s a very negative environment you know.

I’ve had sexual assault … I’ve had a knife put up to my throat and a lot of counselling and a lot of shit.

Normally a person goes to hospital because they are in extremely traumatised state. And yet the only way they can get past the door is by talking about the trauma in great depth with every single person until they are allowed to get help. But if you had a broken bone, a leg bone you’re not asked to jump and down to prove it. And no one wants you to use it, they want you to rest, but in mental health yeah it’s a very dehumanising kind of system of living.

Others described traumatic experiences including violence, losing their children and having shock treatment against their will. One of the issues people raised often was that of feeling that the world can be a frightening place and that they are unsafe:

Fear is one of the biggest, fear yeah fear. Sometimes you’ve got someone who’s got all those things you know and also you’ve got people who stay in their unit because that’s their comfort zone. You know what I mean? They want to stay there because they’re scared [to] go out there out of their comfort zone.

It’s paranoia, its fear of being hurt anymore, it’s a fear of being watched and spoken about and what they are saying isn’t true.

Don’t feel safe here; people didn’t quite understand me and made judgements.

I get really scared when I’m unwell and I think people are out to get me and that’s why I isolate myself from others.

3.1.10 Referral pathways

One of the problems with rehabilitation and social and recreational programs is the stated difficulty of finding out about them. "Unless someone tells you about a service, there is no way to know about it." There seems to be no consistent, up-to-date system of referral to rehabilitation and social support programs. As one consumer puts it:

I was living in a small town and I got very isolated. The family didn't know where to go for help and even today people don't necessarily know where to go for help. You know they don't know about Richmond Fellowship (RF) … it's like a big secret … and even the different agencies don't work together, they seem to be competing against one another. So you're isolated anyway … and if you're seeing a GP you know he might be a good doctor, but I don't think they have a clue of what's out there.

Participants spoke about the need to know about the resources and help that is available. A lot of people are unaware of the range and spread of services. They told us it is hard to find out about services that are available, especially when you are secluded and the referral process is haphazard and can be hard to negotiate.

Many consumers, like the following, found out about specific programs almost by accident:

Well for me at the beginning my sister found out about Richmond Fellowship when I was in hospital and this going back years … she took me there anyway so I moved in and I made friends with the people I was living with. I'm still friends with them today and this was in the mid 90's.

I've got this friend, she used to tell me different things about mental health and about different places you can go and resources, so she told me about the roast on Wednesdays [at Eureka Clubhouse] and she came here and met me here and that's how.

I can remember S saying he was going to the clubhouse and dropping him off and all that, not knowing that it was good, so when I did come in, it was great. I think it was 2005 or something like that, but I'm sure I'd come in a couple of times before, like not for long, just to get S or whatever.

There were consumers, however, who were referred by mental health services, including their caseworker, psychiatrist, mental health team or here NGOs like Colony 47. One person told us "I was referred by PHaMs to Club Haven and it saved my life." Largely people were not referred at all but stumbled on services by word of mouth:

… like Richmond Fellowship, I only found out about that four years after I've been diagnosed and I found out … from a lady that went there regularly. Because they do a lot of social stuff and I didn't even know they existed before then.

Another person told us that she found out about the Red Cross MATES Program from leaflets at the health centre. However others noted that they weren't in the right frame of mind to read flyers about programs.

3.2 Carers

3.2.1 Isolation

Carers in one of the Hobart focus groups, all of whom are mothers of consumers with serious mental health issues, reported the isolation which most often started with the onset of their child's illness. Friendships were lost because friends couldn't cope and isolation increased as a result. For the most part the people cared for by this group still have their times of isolation, some have been isolating continuously for a long time. One woman noted that it "has been 14 years and socialisation is still limited." Some carers made specific reference to the effects of medication which increase the tendency to isolate. One carer noted that her daughter's isolation started at an early age and should have been recognised and addressed in school. Some of the comments we heard from carers regarding the isolation of their loved ones include:

The medication makes him so drowsy. When he's home, he tends to spend a lot of time in his room, can't get motivated to do much but does come out when I'm home and talk. He has a couple of friends who he sees every once in a while. He socialises a little bit but comparing him to other 31 year olds, not much.

When he first became ill, he just wouldn't come out of his bedroom and talk to anyone and just became mute … He was then hospitalised and onto medication and gradually over the 11 or 12 years he's been sick he has a lot more insight into it but he's completely isolated from so many aspects of life.

He had a huge friendship circle, he's a very social person, loved to be social, but his friendships became too hard with the people he was friends with so he lost all his friends. He has made a couple of acquaintance type friends in the meantime and a couple of people from his school go to visit him.

But there are some carers whose loved ones have overcome isolation. One carer reported that since her son started living on his own he has become more socially active, making good friends who encourage him to socialise. Some carers spoke about sport as breaking isolation and helping improve general ability.

It is not surprising to find that many carers themselves isolate. Mostly they become isolated from loss of social groups and friends and sometimes their family members' lack of understanding of severe mental illness. Others become isolated because they feel that they cannot leave their loved one alone as the following comments attest:

Oh yes, I isolated too. I just didn't feel comfortable leaving her. I can remember buying a locked fireproof box and putting even Panadol in it because one of her attempts. She had taken all the Nurofen and all the Panadol, everything she could get her hands on out of the medicine cabinet, so we got to the point where we had to lock every medication away. I … was out for dinner … one night and of course this is before we had mobile phones. I got home about 11pm and [my other daughter] met me at the door and said "I'm so sorry mum but she's tried it again." … So of course when something like that happens, you think well if I'd been home, maybe it wouldn't have happened. So it was matter of keeping her alive and my life pretty much came to a screeching halt.

Well, I became isolated myself in respect to friends as I couldn't expect our friends to take our unwell daughter along as well and then she would be crying and upset and that would be very distressing for them as well as for us.

3.2.2 Relationships

Carer participants told us consistently that it can be hard to maintain relationships with family and friends when one is a mental health carer. Lack of family acceptance increases isolation for both carer and consumer. One carer told us that:

Good heavens, it's changed my life completely. She started when she was about 10 or 11 self-harming and she was bulimic. She got teased at school so she was bullied terribly. I'm still single and she was 10! It's had a huge impact on my life [and] relationships with others in our family. Well, my married daughter is just a wonderful support to both of us and I suppose if anything, it strengthened that relationship and she has a really close relationship with my daughter with a mental illness. I mean, it's been tough on all of us.

In many cases life for the entire family revolved around the loved one with mental illness:

Honestly, my whole family's life for a number of years revolved around R's mental health. The phone would ring … is that R now, is he down again, has he tried to do something to himself? … When I went to Perth to bring him back to Launceston he had a psychiatrist who had absolutely no compassion or understanding. Personally, I think [he was] very unprofessional, he actually told him [R], "what are you doing here? I told you I couldn't do anything more for you here. Just go home, you're wasting my time", to his face.

Often, because the attention of parents becomes focused on the child who is ill and because this child acts in bewildering and sometimes aggressive ways, sibling relationships can become strained and sometimes siblings turn against the brother or sister who is unwell.

His sisters both rejected him so his social isolation is more within the family so he didn't see his older sister. And his younger sister has completely rejected him and virtually has a panic attack when I mention his name almost. So he bullied them, a lot of my hassles with family life were managing his behaviour towards his sisters.

Some carers told us that these relationships were being repaired and this obviously lifts the burden for them, especially when the siblings themselves begin to be part of the "care team".

Nowadays he is starting to reform a relationship with the older sister largely because I have a tendency to harass her to accept him coming with me when I go to see her which isn't very often but that seems to be healing up, that relationship so I am pleased to see that for his benefit. It's coming along quite nicely.

Sometimes consumers feel inadequate compared to their siblings. Relationships with other family members also became an issue as the following carer told us:

I never told my father that my son has schizophrenia, for instance, because I couldn't bear the humiliating tirade I would have received from him. I told my mother, she couldn't speak so I thought I was safe with her 'cause she'd had a stroke, but I couldn't tell my father. The most effect on me has been the grief that remains between J and the loss of relationship with his younger sister who he loved I think, he was terribly cut up that she wouldn't have anything to do with him and at my urging, he wrote her two beautifully written letters, I couldn't write like that, beautiful expression and cards and she never read them, it just broke my heart.

Even where there was the intention to keep up contact with family, carers described issues that made this difficult. One carer told us:

On Christmas Day or Mother's Day when we all get together, we go up over the Tasman Bridge and she's hanging onto the car trying to not vomit. She said this is the worst part and she says "I'm going from a quiet peaceful place to lots of people, traffic, noise, and I want to vomit". But as soon as we arrive at the home, of course at events people bring alcohol, she searches for it or takes her own and within an hour of us being at that family event she is so wiped out she's almost comatose. And the family is so disgusted with her for doing that to them at a family function where it should be happy times … Every one of the rest of my family get on really really well.

Friendships also suffered because of misunderstanding and many carers give up trying to maintain relationships with people who make them feel uncomfortable and ineffective. One carer described a typical situation:

Well, friends probably, just a couple … because people have no idea, they don't understand why I just don't go and tell T to get a job. Even today I still can't believe they still say that. Why do you still go and help him do his housework for goodness sake, he's old enough to be able to do that for himself! Seriously, I just can't believe they can't see it.

We also heard from many carer participants that relationships with spouses become strained, sometimes to breaking point, because of limited time together and non-acceptance of mental illness. Caring becomes especially difficult for those who are on their own as one carer notes:

It was enormous to be honest, I'm not feeling sorry for myself but it's much more difficult when you're a single parent and it's all on you.

3.2.3 Stigma

Stigma is an issue for carers for two reasons. They are concerned about how consumers are treated in society and how this reinforces a desire to isolate and they are often subject to stigma themselves. Their loved ones tell them that they feel "embarrassed" by their mental illness, that they are viewed as "loonies." Carers also witness the self-stigma displayed by the consumers they support. One carer explained the way stigma affected her:

Oh, I was embarrassed, there have been people where I have felt embarrassed. Some people tend to pry a bit and I just say, she's unwell. And they ask what's wrong with her, you don't come out and say my daughter is schizophrenic and she's suicidal all the time and I can't go anywhere or do anything, you don't say that. You just have to hide a lot of it and sometimes I feel uncomfortable for the person that I would be saying that to anyway because that puts them in an awkward situation and they don't know what to say. Or they say, does the father help out? No, he killed himself in the backyard.

Many carers talked about the lack of public understanding that causes them embarrassment to discuss situation. Many of them felt that there should be a public campaign,

… with advertisements on TV that get right to people as well as much better education, right from primary school through high school and college, not that I want to … add more to the curriculum because it's already too much but it's so much about academic things rather than social things and I think that definitely needs to be included in our curriculum. But increased TV ads are needed so that the public is more aware of other mental illnesses besides depression.

And 'are you okay days' are absolutely brilliant so it's getting more and more … I agree, at quite an early age in school it should be talked and talked about appropriately.

3.2.4 Grieving

Carers, mainly mothers, told us about the grief they felt when their children became ill and the hopes and dreams they had nurtured for them were replaced with confusion and fear for their future. Some consumers began to act in ways that got them into difficulties. One carer's daughter became pregnant twice through putting herself in risky situations and being taken advantage of:

… You could see the change, big change, personality, defiance, I was losing her. I had this gorgeous girl … She wasn't violent towards me or anything then and really hasn't been. And then, fell pregnant again but that was all kept a secret from me because I broke down so badly from the first episode. 'Cause I just lost my whole thing as a mother, how could this have happened? I nearly had a breakdown with it all.

Another carer described how close she came to total despair and almost made an irrevocable decision:

Well before she started seeing the man that she is married to it got to the point probably about 6 months before he came on the scene that I had, on more than one occasion, considered ending her life and my own at the same time … It was that bad, and I went to a psychiatrist and I'm on medication because otherwise I wouldn't be able to cope with her situation at all. That's just the way it is.

Isolation causes carers to grieve for lost opportunities. Not only for the consumer, but lost friendships for carers themselves. One carer told us:

It's continual grieving, I haven't stopped grieving for 10 years, that's still there and very hard and feeling so isolated from my usual friendship group who have all got successful children … I've had to be really strong and do a lot of self-talk to be able to manage being in those situations when people are not aware or they are aware and talk about all their lovely successes and not be able to say that, that's been very hard and also for my daughter [sister of the consumer], it's been hard for her because she gets really embarrassed because of that situation. And lost relationships that I've had, his dad has nothing to do with him and I've not had a partner because it's too hard so becoming a single person dealing with mental illness, I've found that really hard and to balance work so that I'm doing something else, it's been very hard to try and keep working and look after myself and my son, it's very isolating.

Grieving increased for some mothers due to of lack of family support, and many talked about the loss of support from their husband for both themselves and their children.

Sometimes the grief is clearly for the lost relationship with the child who has the mental illness. One carer told us that she felt like a failure as a mother and as a result suffered from grief. She went on to describe the disparity between her daughter now and her position in the past:

When she's inside my house, she dresses like a homeless person. Deliberately puts on ragged tracksuits, ragged hems, windcheaters with holes in them, never combs her hair, never showers, I don't know how she doesn't smell. She will go months without a shower. And then I'll come home one day and she'll say 'ta dah', I've just had a shower and washed my hair. First time in about 3 months … Her bedroom is a pigsty. And she won't allow me in there. Has the blinds closed all the time. When she comes in and out, the smell from her bedroom is just appalling. And yet in her wardrobe, she has $950 suits and $450 shoes. When if she lived in Melbourne or Sydney in huge offices where she was the executive assistant to the director of the firm … she has 2 university degrees, she has a degree in business and her first degree from UTAS is in English literature. She's a brilliant, intelligent person but inside my house dresses like a homeless person.

Caring for a person with a mental illness can have major negative physical and mental health impacts on carers. The focus of carers is more often than not entirely centred on the consumer's health, while their own needs are often ignored.

Yes, my mental health has gone down too. I've had mental health issues because it's just such hard work and that's purely because of this environmental situation.

My issues had a double-edged sword in that I also need care so with that concern and lack of sleep, my own mental and physical health went down. It impacted on me also in looking after my youngest and I lost my youngest to her father.

Dependence on carers can be overwhelming and as a result the mental health of the carer suffers.

3.2.5 Support

Many carers told us that they need to have access to services that will help them to stay sane but that adequate, appropriate support for carers is lacking. As one carer participant put it:

The person that is sick …. Need[s] constant support but the carers need that too. If the carer gets sick who will take over? So there needs to be some support.

Carers need a break from responsibility and time for themselves to continue in their caring role, but they need a variety of respite options. Various forms of respite can include:

- Emergency respite if carers become unwell and cannot provide the care required or need to take time off to address the needs of another family member or close friend (e.g. when another child or an aged parent becomes ill or has a crisis).
- Planned respite which can be anything from a few hours to several days in length away from the caring role and this can include a short holiday. Retreats for full-time carers are very necessary and are limited.
- Respite in the form of practical assistance such as with housework or other tasks.
- Creative respite options, which could include massages, a trip to a film or a picnic in a place of natural beauty and other 'treats' for the carer.

Carer support groups are one way that carers can share experience with each other. They told us of the importance of being heard by others who understand their situation because they too have the lived experience of caring. The following is a typical comment on the importance of carer support groups:

I found the carer group that I was involved with, I used to say to them, anybody that would listen, I needed them just as much as they needed me. So I got my benefit from the group, from helping other people.

However, many carers raised the issue of lack of adequate funding for support groups. One woman spoke about holding an informal support group in her own home with no support from any service provider and very limited resources. She has a large number of people who are part of this group, demonstrating the need which exists in the community. She told us:

I'm finding at the moment, 'cause what I do is, I have quite a long list, I get a small group together to have lunch, making sure we have that good nutrition, they come and just play games, it's a quiet time. It's a big list, I have about 120 people on it but it's at my home and I don't want just anyone 'cause I'm thinking about security for everyone.

Carers told us about some of the things that can help support them or that they feel would help them in their caring roles and these include:

- Music is carer's salvation.
- Friends who have dealt with mental illness are good supports.
- A good, understanding GP.
- Carers should have case workers. Need an independent person to open up to.
- More coordination between doctors and service providers.
- Workshops are needed on how to be a carer, taught by people with lived experience.
- More long-term accommodation for the consumer would take the pressure off the carers.

One carer, whose daughter has both a mental illness and an issue with alcohol, spoke about how Al Anon kept her positive:

My weekly meeting at Al-Anon puts me back into a place of serenity, a word they use all the time. I can now look after me and provide a peaceful, happy situation and I would promote Al Anon to everybody, the worldwide program has been proven, just like AA, has been proven to be one of the only ones that works. I am a very grateful recipient of it.

Others spoke about Arafmi, now Mental Health Carers Tasmania, and how that organisation helped them in times of need:

I learnt a lot of the things from Arafmi, they were very helpful.

They were a saviour many times. There was somebody I could talk to and you would always have an answer. You were wonderful.

The mental health system, however, does not often provide the support needed as the following comments attest:

You know, I'll get on a rampage here because it's really frustrating I think dealing with the whole mental health system. It was the same in Victoria. R was in a psych clinic there for months and basically the day she was discharged, it was 'bye, good luck'. No advice for me, I was a single parent, I was on my own, how to care for her, how to deal with it all, where I could go for help. They refer you to a psychiatrist and a psychologist and that's it.

Whenever I have the capacity to do so I talk about how you need to have the coordination between the carer and the family, wife spouse or whatever, and between the professionals and the person with the mental illness, to try and all work together pretty much off the same page and if this integration doesn't happen, you are backing up hill seriously. One of the barriers is the confidentiality barrier … The professionals and clinicians do use it. It's just an excuse. They just can't be bothered … the psychiatrist couldn't tell me anything either because T was so psychotic he wouldn't give permission for his family to know. That is the most ridiculous thing.

Several carers commented on the hindrance that is the confidentiality barrier. Carers reported that privacy and confidentiality were used by mental health professionals to exclude them from the decision-making process and accessing relevant information for the person they care for, even when they had permission from the consumer to be involved. This caused significant impediments to providing care and the overall quality of that care. Carers also felt that they should be included in the treatment plan from the outset.

Some consumers discussed the impact of isolation on children who are dealing with their parent's mental illness. This is an area that needs more investigation and support.

3.2.6 Programs and activities

Carers told us that more programs are needed to support the recovery journey of those they care for and help them move on from isolation and reconnect with the community and activities. Carers felt that many services are not sufficiently resourced to meet consumer needs and that recovery-based services were often difficult to find and access. There also needs to be more support for consumers attempting to connect to mainstream activities. One carer says of her son:

T will try lots, apply to uni or apply to do a course, and he's tried several times with drama 'cause that used to be his forte, that and music. But he can't keep up with it and he drops out. But we've never found anything that's been very successful, he still hopes for his old friends to contact him and wants to do things with them and he does ring them back and they reject him and it's so hard to see.

Another thing carers told us is that there are not enough options that allow consumers to go through their journey at their own pace. They might not be ready to handle money, live in the community or deal with mainstream society for a longer period than current programs allow. As one carer put it:

It might take years and years before they can do it and there's got to be more than just a small number of organisations that provide that sort of program.

There is a reported difficulty of finding the right option out of the very limited choice for consumers. The following two comments are typical of what carers told us:

Well, she went to Colony 47 but it seemed to be sort of not her cup of tea, mostly older men, not homeless but unkempt and that sort of thing and she felt uncomfortable. So that only worked for one day. There's a place called Aurora but that has people who are physically handicapped as well and she found that too distressing for her.

She would be willing to go if it was right for her. She actually … got a volunteer position I think at St. Vincent de Paul in their clothing store … but it was just too stressful, it was just too much for her, handling money and dealing with people.

People with mental health issues can be very sensitive and easily "put off" and sometimes even when a program seems the best option, something goes wrong and the consumer no longer wants to attend. For example, one carer told us:

The best one we have used, and I think we've used all the available avenues, is Aspire, [but] it's always short-lived as somebody will upset her or look sideways at her and she'll find it too stressful. She went to Eureka Clubhouse and that was great, absolutely wonderful as it was right near where I was working anyway. But there was a girl there who became very obsessive about my daughter to the point where she couldn't go anymore. She didn't feel comfortable, and then she was seeing socially one of the men there and that didn't work out either.

Carers mentioned a number of programs that did work for those that they care for including Aspire and Eureka Clubhouse. However many told us that more services are needed to encourage independence for consumers. One carer noted a supported accommodation service which, although it had a substantial backyard, did not provide any activities like gardening or keeping hens. She felt that a program like the one in schools where children learn to grow and cook their own food could be offered. She told us:

A professional gardener or someone who really knows what they are doing, [could teach consumers] how to make compost … let's get somebody from adult education to do a two weekend course … Yes and I'm not saying they need animals or gardeners everywhere, there needs to be a whole room of music, instruments and things. Someone might pick up a guitar and they might have a mental health problem but end up learning something that really touches the soul.

There are very few activities in the community that are not strictly for mental health consumers but are inclusive and provide consumers with opportunities to form connections in the community. One carer told us about how street soccer makes a difference to her son:

Probably about 5 or 6 years ago I saw an ad in the paper and I'd seen it on the 7:30 report about how street soccer was going to every state and they were advertising in the advert about a coach. I was so excited and I cut it out and sent it off to S's case manager because coming … from his case manager, he said oh, wonderful, yes. So he's been going ever since it started in Tasmania except for this break because of his injury. But that's fantastic because it's refugees, anybody who wants to kick for 10 minutes and then if they want, sit down. They don't have to be there all the time, there's no pressure, it's very low key.

Another told us of a therapeutical program that really helped:

She's done a lot of group therapy at the Hobart Clinic which was great. That probably, well she says that of all the years of therapy and psychologists and whatever, it was the best she's had. It really forced her to think, there was a lot of homework involved, it was very confronting, they had to talk openly with their issues and how she felt which she's always found difficult even with a psychiatrist. That was very beneficial. But as far as getting her into a service like Eureka Clubhouse or something like that, we haven't gone down that path. As I said, she's into her acting now and that seems to be a great social outlet for her.

3.2.7 Trauma

Many carers spoke about the trauma histories of their families and its impact on both consumers and carers. This is an area that they feel needs to be better understood generally and more supports need to be provided to help those who deal with it. A history of family trauma that has never been addressed increases both consumer and carer distress and often results in self-stigma and isolation. Typical stories carers told us of trauma history in the family told to us were:

And with my ex-husband, he's got a mental illness but won't admit to it and his father had a lot of mental illness, it started from being a prisoner at 17 during the war and being treated very badly.

And at the very beginning I was actually still married to his father but very close to separation and his father treated him … whipped him, everything … Wouldn't accept that he had a mental illness … Thought he was on drugs etc … and kicked him out of the house twice. So I was driving from place to place looking for him to make sure he was alright.

One carer told us about her abusive childhood, and her resulting inability to love her children because of past trauma:

My brother, sister and I, I'm the middle one of 3 also, were raised in a very violent house, we were belted. We were locked in the black cupboard underneath the stairs with the huntsman spiders. She would come to me, she would grab me around the legs, Mummy, Mummy, wanting some love and affection and I would just freeze and say, off you go, Mummy's busy.

This carer also told us that if she misses 2 or more Al-Anon meetings she starts "to retreat back into the anger of my father's treatment of us."

One carer spoke of the suicide of the consumer's father which happened when the child was four years old. Another carer spoke of the abusive relationship which caused both her and her children to suffer from trauma. The mental illness of a family member is in itself traumatising as is the experience of mental illness and mental health intervention for the consumer. One carer told us that the sibling of the person she cares for needs counselling from the lost relationship with consumer and vice versa.

Carers told us that lack of understanding from friends and other family members causes distress, especially when their trauma histories are not taken seriously. This can happen sometimes when abusive partners "put on a good face" in public, as one carer told us:

If you met my ex-husband, you'd think that yes he's a different fellow but you would not think that he was an abusive man. He comes across as a gentleman. He speaks well, he's so-called intelligent, I don't think he is … he's very calculating, very controlling.

3.2.8 Suicide and self-harm

Suicide attempts, self-harm and suicidal ideation are huge issues for the carers we interviewed. Many of the loved ones of these carers had attempted suicide at least once. Carers described how fear for their loved ones took over their lives and often those of their partners:

We couldn't go anywhere often with our friends, otherwise she had to come with us because she's always very suicidal, most of the time she's very suicidal, so for periods we couldn't leave her on her own for any length of time, otherwise it would be a case.

Her issues started when she was a teenager, well actually before that but she was very suicidal from the age of 14 until about 17. For the first part of her illness, she locked herself in her room basically and that's just the way it was. It was a matter of trying to keep her alive and trying to stop her from self-harming.

When she first attempted suicide, she was living with her father … We then got her into the clinic in Melbourne and my husband ended up taking months off for stress so it was decided that she would come and live with me. She was so incredibly ill and attempted probably 3 more times so there was a period there of 6 to 8 months where it was just pure hell. I had a full time job, fortunately it was only 5 minutes away from the house, my boss was quite understanding so I used to pop home but I'm telling you I would sit out in the car with heart palpitations 'cause I was so scared to go and open her bedroom door.

3.3 Service Providers

The service providers interviewed recognised the benefits of their programs and offered some valuable insights into why these worked for consumers. The following are the main reasons given to us from service providers on the success of their rehabilitation and social support programs:

1. Connection

In many cases it does not matter what activities are being run, consumers still come because the activity is less important than the connection with other people.

2. Peer support

Being with other consumers helps people with mental illness feel more comfortable and can be a way of easing back into society in a safe way. We heard that consumers think it's nice to know that there are people who have been through similar experiences and that "you're not a freak, you're not alone."

3. Recovery Focus

Service providers mentioned the recovery focus of their programs and the expectation that people will transition on from programs. This is an issue that people we interviewed, both consumers and carers, voiced concern about this issue. Changes to programs to avoid "building dependence" means that consumers cannot move through programs at their own pace, but are expected to transition into the community far too early in many cases. Recovery seems to be a concept that has been misappropriated to some degree by both funders and service providers. Recovery should mean having the best, contributing life possible and for some people this may mean staying with a rehabilitation or social community program for a long time. Social activities are key to overcoming isolation and making connections and should remain part of these programs without arbitrary boundaries which are more often than not set by funders.

4. Services are inclusive

Many services are age-limited and cease when people reach 65 but some providers do not always enforce this. A diagnosed mental illness is a requirement for some but not all the services offered, so that consumers who have not yet connected to mental health services can still access them. One service provider said that one of the things you can do to take stigma away from a mental health service is to remove the requirement that you need to have a mental health diagnosis to access it.

5. Consultation and consumer involvement

Most services survey or consult with consumers these days to find out if their needs are being met and if other activities might be required. Service providers who do consult with or survey consumer program participants report a largely positive response which reflects the response from consumers and carers in this study.

There is clearly a desire for consumer involvement at the level of employing staff with a lived experience. Where those staff members are available, the indication is that it works really well and contributes to the comfort and level of involvement of consumers.

6. Funding and resources

Most of the services we spoke to have been evaluated and these evaluations demonstrate a general achievement of goals, including providing a safe place and a sense of community for consumers, preventing, in many cases, frequent re-hospitalisations and providing training in life and basic work skills. Despite this, they are often under-resourced, spread thinly, unable to meet needs for service provision generally and the various needs of consumer participants themselves. They are often told by concumers that they have "changed lives". It seems that one of the issues is a requirement to demonstrate need through rigorous, evidence-based research and this is something that they cannot do within their funding agreements. There is also enough Australian and overseas evidence, as highlighted by the literature review in this work, demonstrating how participation in the community can help consumers stay out of hospital and progress in their recovery journeys. The programs run by the services interviewed are integral to providing this connection because consumers, in their own words, have told us that they feel safe and connected when they participate in these programs. There are just not enough of them.

Section Four
Conclusion

When consumers were deinstitutionalised from mental health 'asylums' there was a fundamental premise that they would be supported to live sustainable and meaningful lives in the community. This study has demonstrated that there is a clear deficit of appropriate and accessible support and rehabilitation services in the community. The consumers and carers interviewed identified a critical shortage of supported accommodation options, rehabilitation services, community drop-in centres, clinical support and access to information about available services. All agreed that the provision of these services is fundamental to an effective framework of community support. There is also great fear that even with the current lack of such services, governments at both state and national level will make further cuts.

On the whole the people we spoke to who have access to services value them highly. Different models of services suit different clients. When people find a service which suits them, even if there are areas that are not perfect, they are grateful for the support they receive.

People also reported the concerns they have experienced with particular services, reinforcing the need for a variety of service options and activities to meet the wide range of needs and expectations of people with mental illness. There were also many comments about issues of vulnerability of people living with mental illness, including: living in poverty and disadvantage, unemployment, family dysfunction and stresses, other health issues and comorbidity, and little opportunity for appropriate and secure accommodation. As a result of their illness, they often lack life skills, including social and occupational skills and all of these issues can exacerbate the symptoms of their illness and social isolation.

As described in this study, paranoia, agoraphobia, and extreme social anxiety are among the many symptoms experienced by people with mental illness. This results in difficulty, often fear, of interacting with a group of strangers. We heard about the difficulty of getting access to information and appropriate referrals to rehabilitation and community social support services. We also heard about financial constraints and difficulties with accessing transport.

Almost all the consumers and carers interviewed spoke about the stigma and shame associated with mental illness and how this can prevent people from accessing clinical and community supports and participating in society.

On the whole, the people we spoke to wanted services and individual care to be planned and implemented collaboratively with consumers and carers to achieve the desired outcomes.

This means that:

- The roles of families and carers are acknowledged, supported and valued in the provision of support and rehabilitation programs.
- Programs which are targeted and evidence-based, supported by appropriate information and referral systems, and evaluated by both staff and participants and their outcomes documented.
- Rehabilitation programs which assist people to achieve the best possible quality of life, building strengths and lessening functional and social disability.
- Identification of individual needs for rehabilitation, including clinical and disability support requirements, which are open to people at all stages of illness, including those with severe psychosocial disability, who may require longer periods of service and whose recovery may be met by having continued opportunities, with no time limit, for organised social opportunities and activities.
- A whole-of-person response to address the needs of all consumers but particularly those with comorbidity, complex disabilities and severe psychosocial disability.
- A whole-life response is required to meet the needs of consumers at each stage of their lives and whatever stage of mental illness.
- The inclusion of peer workers in the development and provision of rehabilitation and social programs.

Rehabilitation programs include social clubs, clubhouse models, support groups and drop-in centres, and other community-based psychosocial rehabilitation centres. The Clubhouse model is an example of one service model that works very well for many of the consumers who participated in this study. Support groups are other examples of self-help organisations that assist people who need support and these too are highly regarded by the consumers and carers who participated in this study. People told us that they needed more access to supportive networks to ensure purposeful support and reinforcement of social capabilities. And that peer support groups should be supported and resourced.

Many of the participants referred to the need for and importance of education and training and the benefits of reciprocity - giving back to the community through volunteering and helping others. It was clear from responses from consumers and carers that natural supports played a large role in helping people connect to community. Opportunities for more proactive programs, connecting people with mental illness to volunteering opportunities and other natural supports in the community are also needed to help them make safe connections and feel that they are leading contributing lives.

In examining the literature available on isolation it is apparent that it is an issue of great impact on the recovery and wellbeing of consumers and their carers. We would go so far as to say that after safe secure and appropriate accommodation social connection is the next most important element in the ability to live the best possible life and begin and continue a journey of recovery. The process and the methods used by different services may differ in different settings, nonetheless, the people in this study felt clearly encouraged to participate actively with others and the community.

From what we were told during this study, it is evident that people with mental health issues and their carers want what everyone else wants. They want safe secure housing, relationships with other people, connection to community, respectful understanding and acceptance of their mental health issues, opportunities to learn, work and play and to be treated like individuals. Unfortunately, many times it seems that they are not recognised as people with the same fears, hopes, strengths and weaknesses as everyone else. The symptoms of mental illnesses vary, with good and bad days, which is similar for people with medical conditions or physical disability. However, the common stereotype of people with mental illness means that the general public often believe that these are people out of touch with reality, unpredictable and potentially violent.

We were told by some consumers that being alone is often a coping mechanism. However, it is clear from the majority of responses, including those from participants who welcomed their time alone, that forced social isolation whether due to the symptoms of illness, or stigma, or lack of accessible services, or other barriers is not conducive to living a participating life and continuing a recovery journey.

What this study found is that people with mental illness and their carers are often isolated, self conscious, suffer from self-stigma, and try to fly “under the radar” for fear of social stigma. Often the people with mental illness are isolated because they have been taken advantage of, discriminated against, bullied, ridiculed, judged and hurt. It is clear that people with mental illness and their carers are often living lonely lives of quiet desperation and this is not good enough. It is time for their voices to be heard. Significant changes need to be made so that people with mental illness, and all too often their carers, no longer feel “stuck in themselves”.

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