# RESEARCH REPORT





# **BUILDING A GOOD LIFE**

The role of natural supports in recovery from mental illness

Naomi Sidebotham





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All names used in this report have been altered to protect the privacy of the research participants.

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# CONTENTS

EXECUTIV	E SUMMARY	1
SUMMARY	OF RECOMMENDATIONS	2
INTRODUC	CTION	3
CHAPTER	I - RECOVERY, SOCIAL INCLUSION AND NATURAL SUPPORTS: WHAT THE RESEARCH TELLS US	6
CHAPTER	2 – FORMAL RESPONSES: NATIONAL AND STATE POLICY CONTEXT	. 10
2.1	National Framework	. 10
2.2	Tasmanian Context	11
CHAPTER	3 – WHAT THE PARTICIPANTS TOLD US	. 13
3.1	What is Recovery?	. 13
3.2	Natural Supports: What Are They and Are They Important?	14
3.3	'I am here totally alone and it's very difficult': Barriers to Accessing Natural Supports	17
3.4	How Can Formal Services Help?	. 19
3.5	'I'm mentally ill but I don't want to associate with mentally ill people': The Value of Peer Support?	20
3.6	Support for the Supports?	. 21
3.7	In an Ideal World	. 22
CHAPTER	4 – WHAT THE SERVICE PROVIDERS TOLD US	
4.1	'I've never worked with anyone who's not socially isolated': How Effective Are Natural Supports?	24
4.2	Barriers to Accessing Natural Supports	
4.3	How Can Formal Services Help?	27
4.4	An Inclusive Community?	. 29
4.5	In an Ideal World	.30
CONCLUS	ION	.33
Sum	Imary of Key Findings	. 35
Reco	ommendations	35
APPENDIX	- HOW THE RESEARCH WAS CONDUCTED	38
REFERENC	ES	. 41

i

# **EXECUTIVE SUMMARY**

This research documents the experiences of 17 people recovering from mental illness across Tasmania. We asked them to tell us about what most helps them in their recovery and enables them to lead full and rewarding lives in their community.

Specifically, we wanted to know about the role of natural supports. Natural supports are those that typically occur in everyday life. They can derive from relationships with family, friends, peers and other social networks, by participation in voluntary and community organisations such as sporting clubs and churches, and through interactions at places within the local community such as cafés, libraries, gyms or the local park. Natural supports are not necessarily confined to relationships with people. They can also include interactions with nature or pets, or as time spent alone meditating, writing or gardening.

The key finding of this research is that a person's natural supports are invaluable in supporting them to live their life to the full. They are often the most important support for people recovering from mental illness. They are important in creating a sense of place and belonging and fostering a sense of wellbeing and inclusion. People with mental illness are no different from anyone else in the community. People want to feel part of the community. They want friends, they want to socialise, they want to contribute, and they want reciprocal relationships with others. They want to be included and welcomed. It is the feelings of engagement and wellbeing that come from having positive natural supports and interactions that were identified by the participants in this research as having central importance to their recovery. They clearly stated that relationships, community inclusion and having something meaningful to do were fundamental to recovery and essential in allowing them to live full and rewarding lives.

The research also found that not everyone has natural supports and that it can often be difficult for people to identify, connect with and build positive supports. Stigma, discrimination and isolation continue to be major barriers for people living with mental illness. Service providers reported that a majority of the people they work with lack natural supports and that in some instances the supports can themselves be a risk factor for people because of their vulnerability and isolation.

Formal services have an important role to play here. They can help people to build, access and maintain positive natural supports. They can:

- be deliberate about talking with people about who and what is important in their lives;
- support people to identify, connect with and build their natural supports. This may be through the provision of opportunities for social interaction or through helping people to build the skills and confidence to be able to identify and access natural supports outside of the formal service framework; and
- promote engagement in activities that people express interest in.

But they also need to be mindful not to replace the role of friends and family who are already a part of a person's life. Recovery and wellbeing is not about one or the other, natural supports or formal services. It is about working together, and both are important for people.

# **SUMMARY OF RECOMMENDATIONS**

## **Recommendation 1**

That formal community-based mental health services prioritise and formalise their focus on natural supports.

## **Recommendation 2**

That formal community-based mental health services ensure that they enquire about existing supports within a person's life and the role that these supports play. This may include identifying whether there are family or friends who can be more formally involved in the service planning process.

## **Recommendation 3**

That formal community-based mental health services continue to provide opportunities for people with mental illness to build their confidence and motivation to engage in social interaction with others and to develop their own natural support networks beyond the formal service framework.

### **Recommendation 4**

That Federal and State Government policy reflect the findings of this research and prioritise and recognise the role of natural supports as support for people living with mental illness.

## **Recommendation 5**

That Federal and State Governments ensure that programs retain the flexibility that services need to be able to facilitate and support a person's individual and unique recovery journey and support them to build positive natural support networks outside the formal service system.

### **Recommendation 6**

That Federal and State Governments and service providers ensure the continuation and expansion of opportunities for education and information for friends and family supporting people with mental illness. It is important that these opportunities are relevant and are easily accessible.

## **Recommendation 7**

That Federal and State Governments and service providers ensure the continuation and expansion of 'respite' opportunities for friends and family supporting people with mental illness to have time for themselves.

## **Recommendation 8**

That Federal and State Governments, service providers and local communities ensure that there is an ongoing community wide anti-stigma, education and awareness campaign at a national and local level designed to encourage people to talk about mental illness and be more aware of, and responsive to, others in their community.

# INTRODUCTION

Allison is 56 years old<sup>1</sup>. After pursuing a professional career for many years and raising her two daughters, she now works part time in a local café in Tasmania and has the opportunity to do many of the things that she never used to have the time or the energy to do. She enjoys gardening, walking her dog, going to art classes and the gym and connecting with nature. She also values spending time with her family, sees her friends as often as she can and is looking forward to going on an overseas trip next year.

Allison is also recovering from a mental illness. She has been ill for many years and has had periods of hospitalisation. Her recovery is hard work.

> It's like if you're doing physiotherapy for a badly broken leg. Some people will give up and the leg will stay twisted. So you have to work hard at it and you've got to work hard on the days when they're shocking.

But she doesn't give up.

I would work very hard doing things and trying things and they wouldn't work and I kept trying. I keep trying all the time. I haven't given up cos I know I can get well.

And as she says, she has, 'really come a long long way'. Her days are, in her words, 'full and worthwhile'.

Allison's story is not unusual. She is one of the many Australians who live with mental illness. Almost one in two of us will experience mental illness at some point in our lives. For one in five of us this will occur within the next 12 months (ABS 2007). Some of us may experience the illness only once and recover fully. Some may experience more than one episode but only occasionally. Some may experience prolonged and frequent periods of illness resulting in extensive and ongoing support needs. And for some people their illness will result in their death. Less than half of us, however, will seek support and assistance for our illness (ABS 2007; Hosie et al. 2014, p.1; Whiteford et al. 2014). For many, this is because of fear, a lack of understanding of mental illness or a denial that we need help. It is also because of the ongoing stigma and discrimination that surrounds mental illness and those who suffer from it (MHFA 2014). Yet early intervention is critical. Left untreated, mental illness can get worse, impacting on many aspects of an individual's life, with far-reaching and sometimes devastating consequences for them, their family and friends and the community as a whole. In 2003, mental illness was estimated to account for 13% of the total burden of disease in Australia (AIHW 2014, p.134). More recently, the Global Burden of Disease Study found that major depressive disorders are the second highest cause of disability in Australia (DoH 2013, p.3). This is supported by data showing that more than one in ten (11.5%) people who reported living with a disability in 2012 suffered mental and behavioural disorders and that almost a third (31%) of people receiving a Disability Support Pension in 2013 had a psychiatric or psychological condition (AIHW 2014, p.134).

At an individual level, the socio-economic disadvantage experienced by people with mental illness, especially severe and persistent illness, is well documented (Boardman et al. 2010; Cameron & Flanagan 2004; AIHW 2014; Duff et al. 2011; MHCT 2014). They are:

> highly vulnerable to the cluster of factors of social disadvantage, such as living in poverty, family breakdown, social isolation, poor general health and oral health status, a high risk of homelessness or inappropriate and insecure accommodation and unemployment. As a result of their illness, they often lack life skills, including social and occupational skills resulting in extreme financial hardship and social marginalisation. This in turn exacerbates the symptoms of their illness ... As a group or individually, people living with serious mental illness face significant barriers to voicing their needs and concerns. A range of factors including social stigma and discrimination, means that this group tends to be largely invisible, essentially excluded from the public and

<sup>&</sup>lt;sup>1</sup> Throughout this report the people we spoke with are referred to by a first name only. All names have been altered to protect the privacy of the research participants.

political domain (Cameron & Flanagan 2004, p.10).

Certainly many of the people we spoke with highlighted that maintaining family connections, having secure housing and being able to afford clothing, food and social activities were daily concerns for them. And nearly all told us that feeling socially included or connected was fundamental to their sense of wellbeing.

The most important fact about mental health, however, is that many people with mental illness will, like Allison, recover and lead fulfilling and rewarding lives (SANE 2014; Deegan 2002). Accessing and receiving appropriate treatment and support is an important component of this recovery. It is the nature of this support that is the focus of this report.

## **Background to the Research**

Formal mental health services, in seeking to promote a person's recovery and social inclusion, have tended to focus predominantly on improving access to education, employment and housing and strengthening an individual's life skills. Whilst undoubtedly important, it is becoming increasingly apparent that these factors alone do not guarantee good inclusion outcomes, and that it is an individual's natural supports that play a central role in facilitating social inclusion and promoting recovery (Glover 2012; Duff et al. 2011; Borg & Davidson 2008).

Natural supports are those that usually occur in our everyday lives. They can derive from relationships with family, peers and other social networks, by participation in voluntary and community organisations, such as sporting clubs and churches, and through interactions at places within the local community such as cafés, libraries, gyms or the local park. Natural supports are not necessarily confined to relationships or interactions with people. They also include connections with nature or pets, or as time spent alone meditating, writing or gardening. These natural supports are important in creating a sense of place and belonging and fostering a sense of wellbeing and inclusion. They help combat feelings of loneliness and can 'have a major impact on whether a person feels demoralised and isolated, or, conversely, confident and whole' (Topor et al. 2006, p.36).

It is these themes of recovery, social connection and natural supports that frame this research. In particular, this report examines the role and effectiveness of natural supports in promoting social inclusion and recovery for people with mental illness, and the extent to which formal services work with people to access, build and maintain these networks of support. It investigates the experiences of recovery through the personal narratives of 17 people recovering from mental illness across Tasmania. A mix of interview and photographic methods were used to explore the main factors that they themselves identified as conducive to their recovery. As well as conducting interviews, we asked them to photograph people and places in their community that they felt were valuable in their recovery. The objective here was to encourage participants to identify things that they found supportive and which they may not have identified simply through conversation<sup>2</sup>. Service providers were also consulted through focus group and individual discussions to identify how they support recovery, how they work with an individual's natural supports and the barriers and challenges they face in doing so.

This report is not intended as another examination of the difficulties of living with mental illness. It is about finding out what helps people to recover from that illness. To this end, it provides commentary and insight on an evolving recovery-oriented service delivery system, identifies gaps in practice and draws some conclusions about how to improve the ways in which mental health services support and maximise access to natural supports. The specific research aims are to:

- identify the range of natural supports utilised by people recovering from mental illness and explore their experiences of accessing, using and maintaining them;
- explore the links between natural supports and social inclusion and recovery;
- review how mental health service providers currently understand and experience their work in assisting people to mobilise natural supports and what opportunities there are to maximise a person's natural supports; and
- develop recommendations about how to maximise access to and use of natural supports for people in order to promote social inclusion and recovery.

The research methods, sampling and limitations of this research are detailed in Appendix A.

There are a number of reasons for undertaking this research at this time. Firstly, recovery based policy and service delivery in mental health is here to stay. It is driven by a push to move services into the background whilst supporting relationships between people, families and the communities in which they live in order to build a good life. This puts professionals 'on tap but not on top' with formal resources being withdrawn once natural supports are in place.

Secondly, it is important that people with experience of mental illness have input into service design. People in recovery have diverse experiences of exclusion and inclusion but the literature has for too long focused on exclusion to the detriment of a thorough understanding of what social *inclusion* means for the individual. This accentuates the need to fully explore what social inclusion means from the perspective of people using services and for potential service users.

Finally, there are currently a range of community-based mental health services delivering a variety of programs aimed at facilitating recovery and social inclusion, and supporting a number of recovery-oriented activities, such as developing life skills, accessing public services, education and transport, fostering closer social and family relationships, assisting with resolving interpersonal conflict and accessing community activities. These might include developing more 'natural' social inclusion activities such as walking clubs, community gardens, cooking classes or peer support activities. These community-based mental health services have a wealth of knowledge and experience about how to access and maintain natural supports and what formal services can and cannot do to assist in this. This research taps into this experience.

### Structure of the Report

- Chapter One of this report provides an overview of recent recovery research, focusing on the role of social inclusion and natural supports in the recovery process.
- Chapter Two outlines the national and state mental health policy context within which mental health services are delivered.
- Chapter Three details what the research participants told us about their experiences of recovery, the role of natural supports in that process and the extent to which formal mental health services work with natural supports.
- Chapter Four details the views of service providers about what, in their experience, best supports the people they work with in recovery.
- This is followed by the conclusion and recommendations.
- The research methods, limitations and demographic profile of the research participants are detailed in Appendix A.

# CHAPTER 1 – RECOVERY, SOCIAL INCLUSION AND NATURAL SUPPORTS: WHAT THE RESEARCH TELLS US

I get really excited about recovery because I think it's fantastic. Each day it's a little bit better and sometimes it's good and sometimes it's bad. But you wake up in the morning and you still go, okay my goal is this. I have a problem with my mental health but I know how to get there. I've just got to get there. But I need support. You can't just do it by yourself. You actually need support (Pete).

Originally the concept of recovery was framed within a medical paradigm that prioritised the eradication of all observable symptoms of mental illness. Essentially, recovery equated to 'cure'. Without such a 'cure' the prognosis for those diagnosed with mental illness was bleak: medication, long-term care, degeneration. The best that could be hoped for was simply to cope (Deegan 2002). Since the 1980s, however, recovery has evolved into a multi-faceted and complex concept that focuses on recovery as a social condition and seeks to move attention away from the illness itself towards a process of self-mastery and management of the illness. This redirection has been largely consumer-driven, with the work of those who have survived mental illness revealing how people with mental illness themselves view and experience recovery (Deegan 1988, 2002). This revised understanding was clearly encapsulated in William Anthony's statement that 'a person with mental illness can recover even though the illness is not "cured" (1993, p.15). He went on to explain that recovery is:

> a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

There has since been much debate about what constitutes recovery, what it seeks to achieve and how best to work towards its realisation. In a 2007 review of the recovery literature, Onken et al. identify a number of key determinants of recovery (p.10). These include:

- recovery is fundamentally about change;
- recovery is a process in which a person confronts individual challenges;
- recovery is about gaining mastery over the illness;
- recovery is about overcoming the impact of the illness; and
- recovery is about enabling social integration and community inclusion.

They explain that recovery involves the interplay of a number of related factors and that the:

dynamic interaction among characteristics of the individual (such as hope), characteristics of the environment (such as opportunities), and characteristics of the exchange between the individual and the environment (such as choice), can promote or hinder recovery (Onken et al. 2007, p.10).

For them, the factors that are vital to an individual's recovery include 'hope, self-determination, agency, meaning/purpose, and awareness/potentiality' (p.10).

Similarly, Ramon et al. (2007) highlight the emphasis placed on the possibility of recovery, that it is not about curing the illness but about managing it in such a way that the individual is able to lead a fulfilling and socially inclusive life. It is a process, an individual journey. They also foreground the importance of the recovery stories of those with a lived experience of mental illness:

From the very beginning personal stories have been and continue to be a powerful developer of and source of validation of key ideas and practices. Much of this literature has both constructed and validated the importance of approaching people as individuals with their own unique journeys within a recovery set of meanings (p.113).

The unique and personal nature of the recovery process, as well as the importance of the individual as an active agent in that process, is also emphasised by Topor et al. (2011). As they explain:

In much of the recent literature on recovery from serious mental illness ... recovery is defined as a process that takes place within the individual. This view corresponds to the way many service users describe their own recovery as finding a way back to oneself. In such situations the aim of the recovery process is defined at the individual level and the central actor in the recovery process is the individual him – or herself (p.90).

These themes are reiterated in a recent Australian study focusing on young people, mental illness and homelessness (Duff et al. 2011). Once again it is the possibility of recovery from mental illness, recovery as an individual process and the importance of focusing on improving quality of life rather than purely mitigating the symptoms of the illness that are identified as common themes here. It is about managing the illness. They conclude that recovery is complex, involving the interaction of a number of biological, psychological and socio-political factors, but that ultimately 'individuals may lead healthy, productive and fulfilling lives despite the ongoing symptoms associated with mental illness' (p.14).

There are a number of recurring themes which can be drawn from this recovery literature that are particularly important in the context of this work.

- Fundamentally, recovery is possible (Harding et al. 1987; Deegan 2002). This does not mean that a person is 'cured' of their illness. Rather, it is about reclaiming a life beyond that illness. Recovery can, in this sense, be understood as a 'personal recovery, underpinned by empowerment, social connectedness and lifelong learning' (Glover 2012, p.16). That is, it is about creating wellbeing by learning from, reflecting upon, making sense of and creating meaning that leads to new action (Glover 2012).
- 2. Recovery is about managing the illness. It is not about the absence of illness, but self-mastery over the symptoms of that illness, so that a



person can live a meaningful and rewarding life despite or within the limitations of the illness.

3. Recovery is a process rather than an outcome. For many, this process is a transformative one 'in which the old self is gradually let go of and a new sense of self emerges' (Deegan 2002, p.6). It:

> is not about going back to who we were, it is a process of becoming new. It is a process of discovering our limits, but it is also a process of discovering how these limits open up new possibilities. Transformation, rather than restoration, becomes our path (Deegan 2002, p.18).

This process is not a simple one. It is not a single event. It is an ongoing journey that occurs over many years, even decades. Nor is it a linear process. It is marked by small steps forward, setbacks and a willingness to try and fail and try again (Anthony 1993, p.19).

4. Recovery is a uniquely *personal* process in which individuals 'will find their own special formula for what promotes their recovery and what does not' (Deegan 1988, p.16). Recovery becomes a self-directed process in which the individual is an active participant, exercising agency and self-determination (Glover 2012).

Essentially, then, recovery can be understood as the maximisation of an individual's wellbeing even with the limitations of the illness. It is not concerned with achieving a cure or an outcome but determining a pathway to a good life. As Patricia Deegan summarises:

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again ... The need is to meet the challenges of the disability and to reestablish a new and valued sense of integrity of purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (1988, p.15).

Underlying much of this work is the importance of social inclusion, or community integration, to recovery. Social inclusion can be taken here to mean belonging to a community that makes people feel valued and protects wellbeing.

> Social inclusion means building a nation in which all Australians have the opportunity and support they need to participate fully in the nation's economic and community life, develop their own potential and be treated with dignity and respect (ASIB 2009, p.2).

At an individual level, social inclusion involves feeling included through friendships, feeling worthwhile as a contributing member of society and feeling positive and hopeful (Davidson et al. 2001). It counters the isolation that people with mental illness experience, and which evidence indicates has a significant detrimental impact on their wellbeing and is a major barrier to their recovery (MHCT 2014). As such, recovery can be seen as a social endeavour. Whilst it is important to emphasise the uniquely individual nature of the recovery process, we should not allow this to 'prevent us from seeing that the road to recovery is also a social process' (Topor et al. 2011, p.91). Recovery is not something that occurs in a vacuum, but 'within a web of relations, including the individual, family and community' (AHMAC 2013, p.11).

This necessarily raises the question of how we, as a community, can best foster and support social inclusion. One way is to ensure that people with mental illness have access to appropriate material conditions. These include secure housing, sufficient financial resources, meaningful activity (whether employment, education or volunteering) and access to community resources (Topor et al. 2011; Duff et al. 2011). Equally important, however, are the relationships that people with mental illness have with others such as family and friends (MHCT 2014; Borg & Davidson 2008; Topor et al. 2006), and their interactions with their surroundings, including the natural environment, their home and social organisations. It is these 'natural' supports that evidence shows play a key role in facilitating social inclusion. This is not surprising. Natural supports are an important resource for everyone, not only those with mental illness.

A solid support system can make a significant difference to a person's life. Studies have shown that individuals with a greater diversity of relationships and/or involvement in a broad range of social activities have healthier lives and live longer than those who lack such supports (UPenn n.d.). For people with mental illness natural supports are equally, if not more, important. They provide engagement, hope and encouragement as well as opportunities for inclusion and the development of new relationships (Bradshaw et al. 2007; Topor et al. 2011; Borg & Davidson 2008). They can foster a sense of empowerment and independence and even reduce the need for reliance on formal services. Yet:

according to research, people with mental illness may have social networks half the size of the networks among the general population (UPenn n.d.).

Given that this is the case, it is important:

for mental health providers to recognize that what promotes recovery is not simply the array of mental health services. Also essential to recovery are non-mental health activities and organizations, e.g., sports, clubs, adult education, and churches. There are many paths to recovery (Anthony 1993, p.18).

Certainly the people we spoke with emphasised the importance of natural supports in their recovery. For some this support took the form of family, for others it was friends or social clubs. And for some it included time spent writing, reading or gardening. In all instances, however, where they did identify natural supports as being part of their life, regardless of the nature of those supports, they talked about them as central to their ongoing wellbeing.

The positive role that natural supports can play in recovery is an under-researched theme in the Australian context. While it is recognised that they can be significant to the recovery process, little attention has been given to how best to assist an individual to build, access and maintain their natural supports and, in particular, the role of formal services in this. Similarly, while much research has focused on what is meant by social *exclusion* it is often to the detriment of what social inclusion means to the individual. There is a strong need to explore what social inclusion means from the perspective of people accessing mental health services. By talking to people with a lived experience of mental illness, this research begins to examine these issues. It marries the two themes of social inclusion and natural supports. It seeks to find out from people recovering from mental illness how, in their experience, natural supports provide a valuable support in facilitating their social inclusion and recovery.

# CHAPTER 2 – FORMAL RESPONSES: NATIONAL AND STATE POLICY CONTEXT

In 1992 federal, state and territory governments in Australia came together to endorse the National Mental Health Strategy. This was the first time that governments had agreed to a national coordinated and bi-partisan approach to the development and provision of public mental health services, which had previously been the exclusive responsibility of state and territory governments. Since this time there has been a proliferation of reports, inquiries, strategies and policies directing mental health reform, that have progressively emphasised the need for structural change, prevention and early intervention, de-stigmatisation, recovery-oriented service frameworks and the recognition of the importance, expertise and value of the lived experience of people with mental illness.

This chapter maps out the complex web of policy statements, plans and whole of government initiatives that have directed this reform process. It briefly describes key developments and summarises the landscape as it is today in 2014, at both a national and state level, thereby providing the context for the experiences of the people we spoke with and the recommendations that are contained within this report.

# 2.1 National Framework

The National Mental Health Strategy commits all governments, both federal and state, to undertake actions to promote and achieve its objectives and to collaborate on national policy and service development issues (DoHA 2013, p.17). Broadly, its aims are to:

- where possible, prevent the development of mental disorder;
- reduce the impact of mental disorders on individuals, families and the community; and
- assure the rights of people with mental disorder (AHM 2003, p.6).

The Strategy has been progressed through a series of policies and plans, commencing with the *National Mental Health Policy 1992* (AHM 1992c) and the *First National Mental Health Plan 1992-1997* (AHM 1992b). The Policy encapsulates the objectives of the Strategy and stipulates twelve priority areas to be actioned by governments, aimed at promoting a whole of government response to mental health, the integration of mental health services with the mainstream health sector, early intervention, promotion of better mental health, and the protection of the rights of people with mental illness (Whiteford 2002, p.210).

These objectives were the focus of the first three national mental health plans. The first plan was directed primarily at structural reform, with a particular emphasis on the reduction of the number of stand-alone psychiatric hospitals and an increase in the range and availability of community-based care alternatives (DoHA 2013, p.21). This focus was expanded in the Second National Mental Health Plan 1998-2003 (AHM 1998) to incorporate additional areas such as mental illness prevention, mental health promotion and the integration of public mental health services with private services and the general health sector. In addition, whereas the first plan had addressed predominantly severe and disabling illnesses, the second included more high prevalence conditions such as anxiety and depression (DoHA 2013, p.21). The Third National Mental Health Plan 2003-2008 (AHM 2003) continued the emphasis on mental health promotion, mental illness prevention and the necessity of a whole of government approach to mental health reform. In addition, it prioritised improving service quality, fostering innovation, recognising the rights of consumers and carers and the importance of recovery-oriented service delivery (DoHA 2013, p.21; Cameron & Flanagan 2004, p.26).

Before the end of the third plan, two significant whole of government initiatives were endorsed by governments: the National Action Plan on Mental Health 2006 (COAG 2006) and the revised National Mental Health Policy 2008 (AHM 2008). The National Action Plan re-affirmed the ongoing commitment to mental health promotion, early intervention and prevention. Importantly, it also emphasised the need for the delivery of services to people with mental illness in areas other than health care, such as housing, employment, education and correctional services, and the expanding role of the non-government sector in the provision of support services (DoHA 2013, p.22). The revised National Mental Health Policy reinforced the whole of government approach that was articulated in the National Action Plan. It provides:

> an overarching vision for a mental health system that enables recovery, prevents and detects mental illness early, and ensures that all Australians with a mental illness can access effective and appropriate treatment and community support to enable them to participate fully in the community (DoHA 2013, p.22).

It is against this background that the *Fourth National Mental Health Plan 2009-2014* (AHM 2009) was developed. This plan focuses on five priority areas for national action (AHM 2009, p.11). These areas include social inclusion and recovery, prevention and early intervention, service access, coordination and continuing care, quality improvement and innovation, and accountability. The plan promotes a flexible whole of government response to mental health.

Currently, the National Mental Health Commission is conducting a review of existing mental health services and programs across all levels of government as well as the non-government and private sectors. The Commission is examining and assessing the effectiveness and efficiency of all services that provide support to people with a mental illness, and their families and supports, to lead a contributing and productive life within the community. It is anticipated that the final report will be completed by late 2014. It will shape the future direction of mental health services at both a national and local level. In addition, a further major reform is the implementation of the National Disability Insurance Scheme for people with psychosocial disability. It is anticipated that this will present a range of opportunities for people to choose the kind of support they want, including support with social engagement and occupation.

# 2.2 Tasmanian Context

In line with national policy direction, Tasmania's mental health system has also undergone significant change and development over the past decade. Since the Bridging the Gap Review in 2004 (DHHS 2004) there has been greater emphasis placed on the role of the community sector in providing mental health services, the importance of the consumer and carer voice in shaping mental health services and, more recently, a focus on strengthening community support for consumers (DHHS 2014, pp.6-7). The mental health service system in Tasmania now involves many stakeholders including consumers, their families and carers, federal and state governments, community sector organisations, primary health care and private providers. Community sector organisations, in particular, play a vital role in providing a breadth of services to people experiencing mental illness. These include:

> supported accommodation, residential rehabilitation, individual packages of care, community based recovery and rehabilitation programs, services for children and families, peer support groups, advocacy and peak body representation for consumers, carers and service providers (DHHS 2014, p.9).

The current policy framework for the delivery of mental health services in Tasmania is directed by the Mental Health Services Strategic Plan 2006-2011 (DHHS 2006) which establishes a set of guidelines aimed at achieving better mental health outcomes for the Tasmanian community. It contains a number of strategic goals, including promoting a model of mental health care that is centred on consumers, promotes recovery, is equitable and efficient and ensures that mental health services staff work effectively with consumers, their families and carers. This sits alongside the Action Plan for Implementing Promotion, Prevention and Early Intervention (PPEI) Approaches in Tasmania (DHHS 2009). This plan focuses on a whole of population approach to 'maintaining mental health, reducing the prevalence and minimising the impact of mental illness' (DHHS 2009, p.2). It stipulates a number of priority areas, including the promotion of mental health and wellbeing across both government and the community, and building capacity across sectors and within the community as a whole to implement initiatives supporting mental health and wellbeing (DHHS 2009, p.2).

Mental health services in Tasmania are about to undergo review. The *Rethink Mental Health Project* is part of the Tasmanian government's election commitment to 'develop an integrated Tasmanian mental health system that provides support in the right place, at the right time and with clear signposts about where and how to get help' (DHHS 2014, p.5). The project will map existing services, both government and non-government, in Tasmania and identify service gaps and barriers to accessing services and treatment. It will make recommendations for system reform and seeks to develop a long term plan for mental health that will achieve better outcomes for consumers, their families and carers.

These policy frameworks clearly direct us to a focus on early intervention, recovery and social inclusion. It is within this context that our exploration of natural supports and their role sits.

# CHAPTER 3 – WHAT THE PARTICIPANTS TOLD US

I've got quite a strong circle of friends here which is something I've not had before. So because I've got a strong circle of friends, social supports and volunteering supports ... I can't see myself moving away (Lynette).



Friends can play a vital role in recovery from mental illness. So can family, being involved in social organisations or contributing to the community through volunteering. This is what the research literature tells us. It is also evidenced in the lives of the people that we interviewed across Tasmania. Their response was almost unanimous. Good natural support networks can greatly facilitate the recovery process.

This chapter analyses what the participants in this research told us about their understanding of recovery and about what they think helps them most in working towards this. Their responses support and build on much of the recovery literature reviewed in Chapter Two and begin to address some of the gaps identified in that research. The issues we discussed with them included what they thought their natural supports were, how they were beneficial and if they thought these natural supports contributed to recovery. They were also asked how formal services worked with them to maintain these natural supports.

# 3.1 What is Recovery?

For the participants in this research recovery is a uniquely individual and personal process. They each told us of different experiences, barriers, setbacks and successes. But whilst they had divergent experiences of recovery and had adopted different coping strategies and techniques, all were concerned with what recovery meant for them, not what it meant for others, whether family, friends or professionals. And for them, recovery is about being well enough to be able to do the things that they want to do with their lives. It is about not being limited or defined by their illness. It is about becoming a person or 'normal' again, whatever that means to each person, developing the ability to get on with life despite their illness and getting their life back. They describe recovery as their renewed ability to deal with normal life and as waking up in the morning and 'saying okay, let's go do it'. John explains it as:

I started to come back to being a person again. Yes I've got flaws. Yes I've got mental illness but it doesn't define who I am. It's a part of me so deal with it. For a long time I didn't have that strength.

These understandings of recovery are underpinned by a sense of positivity and motivation, of resilience and hard work. Some of the participants identified as being further progressed in their recovery than others, but they nearly all expressed hope and optimism about this process.

> Things have been really good for me. One of the longest stretches I've had. I've learnt strategies. Everyone has their down days. But it's pushing through that barrier and not thinking I'm going to get bad again (Matthew).

This does not mean that recovery is easy. It is:

bloody hard work ... And it's two step forwards and one step back ... I would have preferred to take a pill but you can't and so you have your coping strategies and your plans and accept it when you don't do well and praise yourself when you do (Amanda).

The sense of optimism, that recovery is possible, was not a sentiment expressed by everyone however. Michael, for example, despite stating that recovery was theoretically possible, did not feel that this was the case for him.

> I've been trying to recover and cope better with my depression and that sort of thing since I was first diagnosed in 1987 and I haven't really made much progress. Despite all the things I have done in between I'm not coping any better, probably worse in some ways.

The key question addressed in this research is the extent to which natural supports contribute to people feeling positive and that they are recovering.



# 3.2 Natural Supports: What Are They and Are They Important?

My interpretation of natural supports is having friends, church and other things who actually liked and loved me through my illness and are still there. It's incredible. So they must have seen what was good in me not what was bad. These people are really important to me (Alan).

Natural supports are those that generally occur in our everyday lives. As discussed above, they are relationships that arise directly from our interactions with people and places in our community as opposed to formal service providers, such as counsellors, psychologists, support workers or case managers. They are important in creating a sense of place and belonging and fostering a sense of wellbeing, inclusion and self-worth.

Most of the people we interviewed identified that it was these natural supports that were essential in their recovery. As one participant said:

They are probably one of the most important things you can get. You can rely on that much more than you can a real service ... Well you don't have to make an appointment with your friends and family (Luke).

Most were also able to list at least four or five supports that were particularly important to them. Even those who stated that they had no, or very limited, support went on to discuss two or three people or supports that did play an important role in their lives. And while the range and nature of these supports varied, their importance universally lay in the feelings of empowerment and inclusion that they fostered in the participants. The most commonly talked about supports included family, being involved in a creative arts or music group, church, friends and the natural environment. Luke, for example, talked about the benefit of hiking and bushwalking, and Amanda told us how walking made her feel relaxed. For John simply going to the beach was a big support.

When you get troubled and you just need to have a bit of a rest it's nice just to come and stare at the waves and walk along the beach. It's nice, very calming and very nice ... It's peaceful.

It was, however, relationships and interactions with others that were identified as particularly significant. Those participants with supportive partners described how important they were in supporting them through their illness and helping them to maintain good health. As one participant explained, her current partner has:

been an absolute darling in trying to get me to exercise, eat well and do all of that. So yes he's a beautiful support (Lynette).

For others, it was their parents or children who filled this role.

The best support is to have a mum and dad that understands me. Which they did. Because mum stuck through me thick and thin (Michelle).

Friends were likewise deemed an essential support. Amanda, for example, expressed that the time she spent with her 'ordinary' friends was invaluable because they didn't talk about mental illness. It was simply not part of that friendship. It was her 'time off'.

Every second Saturday two friends and I go op shop shopping all day and we have a counter meal. Now we're all going through stresses but we have a golden rule. It's never been said but we never talk about our problems. I might say I've had a bad week and they might say we have too but we just shop all day and have fun. That's our relaxation. So I've got to really depend on that for a support. Beyond these more immediate and intimate relationships, it was feeling part of the wider community that was perceived as critical by many participants. This is for a number of reasons, from the support they derived from simple daily interactions with the person in the local shop to the opportunity to make friends with someone they particularly connected with. Alan, for example, said that everybody in his community was important in some way.

Everyone in the chemist and the supermarket and the newsagent and the library. The fact that they have been nice to me, for want of a better word, and not like, look out, watch him, he's a bit "wooooo".

He included a wide variety of people and places in his community including the man who runs the service station, the lady in the confectionary shop and the proprietor of the local gallery. Similarly, Allison talked of going to the gym on days when she really didn't want to. The simple activity of going meant that she:

> talked to the people at the desk, and they are such nice supportive people. They really didn't know how important they were in my life. They just thought they meet me at the desk, but it was really important that they were giving me support. And you'd come out after that hour and you'd feel better. So that's been very important.

For Alan it went a step further. His interactions at the local gallery meant that he formed a significant friendship with the proprietor's husband.

> When I go around there he gets me into his workshop. He's a good guy. We share a lot in common. Not just in church and not just church stuff. We like old films and TV series and music. And he's always surprised by my knowledge of things and trivia, which I love. He's a good support.

Alan's community also included his local church, which he identified as one of his main supports as the people there were really important to him. Involvement in a church community was something valued by many of the people we spoke with. Luke, for example, described the importance of his church as 'massive'. He explained that having faith and praying:

just helps mentally. I think it's really good for your mind. Even if what you believe in ... turns out to be false or whatever, at the end of the day you've still done something that's worthwhile and improved your overall life. So I feel that it's a win win no matter what. But I think doing that has really helped me to understand things more and it really helps to be able to talk, even if you're praying or something. It helps to be able to get it off your chest. You pray before you go to bed at night. It's the same as writing it down in a book. And it just helps.

For Amanda, just reading the Bible helps with her anxiety. She is also very involved in her local church. She loves the music, the sermon, the messages, the coffee and the time after the service spent with others.

Pets, technology and activities such as gardening were also identified as significant by many participants. Darryn and Michelle, for example, particularly valued their pets. Darryn's dogs bring him a lot of joy and pleasure and he feels really close to them. For Michelle when she is 'feeling down it's the comfort to know that the dogs are there'. She:

can just pick one up and talk to her, even though she can't understand what I'm saying. It's like a comfort blanket.

Some participants really valued having access to a computer. Matthew enjoyed using it as a way of communicating through email, while Amanda described Facebook and participating in chatrooms as one of her most important supports. She found it easier to talk to this online community than her everyday friends.

> My everyday friends don't know my struggles. They know I struggle and they know I am not right but I would never say in detail.

For Jackie, who lives alone, it was the television that provided a great support. She explained that she can watch it day and night so that she doesn't get scared or lonely.

Participation in education, employment and volunteering was something that gave some of the participants a sense of self-worth and of contributing to the community. Allison enjoyed working in a local café and Darryn relished his work at a bible college and his casual farmhand jobs. People also commented on the value that they derived from volunteering:

I volunteered with the regional arts group. I've gone back to volunteering with them again, assisting with the youth group there. That's been an important connection with the local artists in the town. A sense of belonging is important ... Early on ... I stopped at a neighbourhood house ... I went back there and volunteered. That's been important. It's got me out of the house, feeling like I'm valued, that I'm not the totally useless, worthless, unequal person that people like psychiatrists and parents tried to tell me I was (Lynette).

Luke valued his involvement with St John's Ambulance because he felt he was actively contributing to his local community. It made him feel useful and increased his self-worth. He also identified another natural support that he thought was important: a sense of humour.

I think one of the biggest natural supports of all is just having a sense of humour. Being able to make a joke out of it. Cos that's one thing, no matter how bad a situation I've been in I've always been able to make a joke about it. That's probably the thing I value the most. If anyone asked me what I like about myself or what I can brag about it would probably be that. So I think encouraging a sense of humour is really good. And all of my counsellors have always really had a sense of humour and been able to joke about things. Just being able to have a laugh helps so much.

It is clear from the above discussion that what is important is not so much what natural supports people have, but how these supports make them feel. The recurring theme from the people we spoke with was that, whatever their form, natural supports helped them to feel confident, included and optimistic, and contributed in some way to their sense of self-worth and purpose. This should come as no surprise. As the World Health Organization states, good mental health is connected with meaningful contribution, and good overall health is 'a state of complete physical, mental and social well-being' (WHO 2006, p.1, emphasis added). Certainly, many of the participants in this research emphasised that feeling socially included, having reciprocal relationships with people and being a contributing member of the community were of paramount importance to them. As they stated, 'to be healthy you needed to be connected', 'your recovery's got to be in the community' and 'giving to other people and doing things for other people is part of the recovery'. And clearly one of the most important ways in which natural supports can help is by fostering this social connection.

# 3.3 'I am here totally alone and it's very difficult': Barriers to Accessing Natural Supports

We know that social inclusion is important. As shown above, many participants just wanted friends and to be included. Yet inclusion can be difficult to achieve and isolation was identified by many as a major barrier to recovery, and as a strong contributing factor to their ill health. As Matthew explained:

> I think it's well known that when people suffer from mental health they isolate themselves. They don't want to be involved with anyone and they have an inferiority complex. They don't want to see anyone, they don't want to talk to anyone.

This was highlighted by a number of participants. Jackie, who is 59, thought that there simply weren't enough social options for people her age. Likewise, Pete just wanted someone to go and have a beer and a chat with. Instead, he felt that:

> I don't have a life ... I have a flat which is at the back of a house from my mother's. So I've got a bedroom and a lounge room and I 'live' there and my mother will come and knock on the door if she wants to go and do something.

### Gail explained that:

I don't really go and visit people. I just do what I've got to do and then I go back home. And if I'm really feeling down I just lock the front door and don't let on I'm home. People have come of a night and think I'm not home cos I just have the lights off and sometimes I watch TV.

This isolation can be exacerbated by a range of other barriers including stigma, discrimination, lack of confidence and poverty. Some participants expressed that they struggled to make ends meet, while others were concerned about stigma and discrimination and the impact that it can have on interactions with the community and family by making them feel unworthy and unequal.

Overcoming these barriers to inclusion requires support, and, as stated above, natural supports are an important resource in countering isolation and fostering connection. Yet accessing natural supports themselves is not always easy. It can require hard work and perseverance to access and maintain them. Allison, for example, commented that she has had to work very hard to create all the supports she had in her life. Similarly, Darryn felt that 'you have to take some measures yourself, you can't rely on everything being done for you', and Matthew observed that 'we could have sat back and felt sorry for ourselves but we thought we've got to join things where we can meet people'. And for Alan many of his natural supports had developed because of his wife: 'her friends became my friends'.



It is not, however, always a positive story. There were many participants who talked about the difficulties of accessing and maintaining a natural support network and that this only served to increase their feelings of isolation. They struggled with finding friendships, maintaining family connections and having people who they could talk to and interact with for intellectual stimulation. Some participants highlighted that they did not have a close friend.

I haven't got a close mate, like a male friend, a best mate. I haven't got anyone like that and probably that's been a bit of a struggle for me (Darryn).

Similarly, Pete said he'd never had a close friend. He had had a lot of colleagues. But once he lost his job he lost them as well. As a result, he spends most of his time sitting at home alone. What he really wanted was to be able to go out and 'talk to people and have conversations with people' about philosophical and social issues, and not just the footy. Michael expressed a similar feeling, saying 'there's nowhere where I regularly get conversation with anybody, even at church'. For other participants the difficulty was finding friends in their age group, while for Tracey and Gail it was the lack of sincerity of their friends that concerned them.

And I've got all these people who say they're my friends, I've got these three people who always say they're my friends and not one of them came to mum's funeral. Not one of them was there for me through the bad time. And they're not even here now ... I just feel sad because I don't feel like I have any friends (Gail). Lack of family support was also keenly felt by those who didn't have it. They indicated that this was something that they missed and felt would have been beneficial in supporting them in their recovery. As Jackie puts it, 'I am here totally alone and it's very difficult because I have been very very sick'. Others were disappointed that their families were not always interested or proactive in maintaining that relationship. Amanda, for example, was frustrated by her children's lack of effort in visiting her despite the fact that she didn't have a car.

> And this is another tension with my kids. Cos in the week I'll catch a bus to them ... And I don't care. It's only \$3. But two of them have got the weekends free and they want to see me on the weekend but they're not prepared to drive down to me ... So I don't see them as much as I'd like to. None of them contacted me for mother's day.

Similarly, Gail commented that she was going to Hobart as she was:

Making a point of keeping up with my family. Just cos they're not keeping up with me doesn't mean that I'll do the same thing.

For others, the stigma associated with mental illness meant that they had less contact than they may otherwise have liked. And in the case of Tracey, sadly she felt that the stigma had effectively destroyed her relationship with her family.

The impact of not having these networks of support for these participants was immense. It reinforced their feelings of isolation and in some cases made them reluctant to leave the house. It impeded their opportunities to interact with others and develop communication and social skills, and it reinforced their feelings of self-stigma. They consistently identified that what they really wanted was more friends, greater connection with family or just someone that they can talk to. Gail, for example, thought that she would, in the future, like more friends. Michael commented that what would help him most would be:

> Just to have someone to talk to more often. If I had someone to talk to two or three times a week that would make a difference. I'm not expecting them to solve my problems but it's just having someone else to talk to cos I don't have anyone else.

And for Jackie, she envied her neighbour who has:

The life I'd like. She has lots of family, lots of friends. She's got a beautiful boyfriend ... She volunteers. She has lots of girlfriends, her son, her daughter, she goes to visit her dad.

There are a number of questions that emerge as a result of the above observations. Firstly, what is the role of formal services in helping people to build their natural supports? Secondly, what is the value of peer support, whether it arises 'naturally', is organised by formal services or occurs through involvement in consumer representative organisations? And thirdly, what is the impact on those, whether family, friends or the community, who are providing this support?

# 3.4 How Can Formal Services Help?

According to the people we spoke with, formal services are important. They assist with a range of supports, from assisting with daily tasks and developing strategies for living with mental illness, to building the skills and self confidence required to lead a full and rewarding life. Many of the participants in this research also thought that formal services had a major role to play in helping people to access and maintain their natural supports. This may be through actively introducing people to different supports or through building the skills and confidence needed to enable people to build their own support networks. When asked if formal services had helped him to build his natural supports, Alan, for example, replied 'definitely yes' and Luke thought that his services had promoted the development of his natural supports through encouraging him to pursue his love of bushwalking and by showing an interest in how he was progressing.

> They really really encourage me to go out and go bushwalking. And they always ask me how are you going with that? When I stop and say I just don't have the time at the moment they say well try to get 30 minutes a day, keep on top of it and it will help with your depression, which is really helpful. Whereas some other services are like well that's fair enough and just leave it.

Jackie explained how her participation in one mental health program helped her to build the confidence to go out alone and interact with her local community.

> So my girlfriend rings me and says that her boyfriend is going to drop her at the community fair, which is a lot of rubbish. So do you know what I did. I went by myself. Now I wouldn't have done that before. I would have stayed home, felt sorry for myself, felt disappointed, internalised it and got upset. And I thought no, you're ready to go, so go. So I went. And I'll tell you I had a lovely time.

And for Tracey it was the practical help that she valued and that she felt allowed her to then work on building her natural supports.

> Especially ... in providing me with somewhere to live ... Just constant ongoing stability so I can focus on the other things, the important things like getting my health back and on every platform; social, health, financial, friends.

What is clear is that participants value services that facilitate social inclusion and connections by hosting activities, such as BBQs and other social outings, and help people to build their skills and confidence to be able to create those connections themselves outside the formal service framework. Darryn, for example, really appreciated the help provided by one local service in North West Tasmania, commenting that:

> They are a good organisation. They do some good work. They put on some really good activities for all sorts of people, older people, younger ones, a lot of community activities. They are a very community minded organisation.

Likewise, Matthew was particularly complimentary about a men's shed based in rural Tasmania:

I can't speak highly enough [about it] ... it's been absolutely marvellous and I can say that on behalf of the other eight or nine chaps that are doing this with me ... They all say this is the greatest thing and no one wants it to stop. Not everyone, however, agreed that these kinds of activities are always beneficial. Michael, for example, wanted something a bit more challenging and stimulating. He noted that:

> Most of the agencies are making an effort to have BBQs and to have things together and for those that can handle that it's okay as far as it goes ... That's fine ... I've gone to a lot of those things. I'm never comfortable but I've gone along. But for somebody that either isn't comfortable with those things or needs something a bit more intellectual or needs a bit more one to one contact there's always too many limits on it.

A common thread in participants' responses was that they were particularly complimentary about services that went the extra step, where workers showed a legitimate interest in their wellbeing and were friendly and caring with them. Lynette particularly valued the support and encouragement she received from her support worker when she voiced an interest in volunteering. For her it was not just about the formal support she received, but about being able to share with her worker that this was something she wanted to do and getting positive reinforcement to do it. Similarly, Luke really appreciated:

The attitude that you can do it, keep focused, stay on track, you can do it. It's never give up. It's always keep going, you can get through it. So that's probably the biggest thing that helps. Whenever you talk to someone all the time no matter how bad it is, it's always you can do it, is there anything we can do. There's always that question what can we do, which is really helpful, even if there is nothing they can do. Just to be asked it shows care and compassion so it is good.

Care and compassion were also factors that were important for John. Knowing that there was someone who he could almost count on as a friend and who was interested in his life and his family was an important factor in his recovery.

I had a support worker who would come in once a week and take me into town, would bring me in here quite a lot and she was great. She was like a friend. It was nice to have a support worker who was just being there. We'd have lots of conversations, lots of fun, lots of laughs. Cos on a bad day she would try her hardest to make me laugh. It is the provision of positive social interaction, opportunities for the development of other ongoing interactions and workers really caring for their wellbeing and being available that participants clearly valued. These factors made people feel worthwhile and hopeful. As one participant said of her worker:

> She sat down and looked at me and her eyes sparkled and I thought this girl thinks that there is some hope (Jackie).

# 3.5 'I'm mentally ill but I don't want to associate with mentally ill people': The Value of Peer Support?

We were interested in finding out from participants whether or not they found peer support to be a valuable or useful support in their recovery. By peer support we mean socialising or sharing with people who have had similar experiences, as well as more formal support networks such as those that derive from participation in consumer representative or advisory organisations. Participants' responses varied greatly. Jackie had absolutely no interest in associating with people with mental illness. She didn't think that would do her 'any good at all'. As she puts it:

> I just want to live a normal life with normal people. I'm mentally ill but I don't want to associate with mentally ill people.

Similarly, neither Michael nor Pete had found peer support to be beneficial. For Michael he simply couldn't:

> find anyone on the same level in terms of what's going on around them with the same awareness of their own problems and experience.

And while for Allison peer support had played an important role earlier on in her illness, now that she is recovering she is drifting away from those supports. Most participants, however, did value peer support. They felt that being able to socialise with people who had similar experiences and who understood what they were going through was invaluable. Darryn, for example, felt that it was good to:

share ideas and encourage one another to learn from one another and see how other people cope in similar situations.

Matthew similarly valued the benefits of being able to 'exchange ideas and encourage one another' at his men's shed.

> Through the afternoon we stop and have tea and coffee and we sit around the table and we discuss mental health and we ask each one how they've been going for the last week and whether they've found something that's helped them. Or if there's something that's upset them we try to sort that out, encourage them. So it's not just making something. It's that discussion time and encouraging one and other.

And for Tracey just being with people with mental illness was important. 'We don't have to talk about it. We just know.'

For many of our participants being involved in some kind of consumer representative or advisory group was important to them. Alan enjoyed meeting other people with a lived experience. He felt connected with them, like they were all in it together. And importantly, 'everybody knows they're not going to be judged I suppose'. John similarly commented that it's nice to be able to sit and talk with people that understand mental illness without feeling strange, to be able to connect with them where there is no stigma. For John, and for Michelle, involvement in consumer representative organisations also made them feel important and worthwhile.

> It gets me mixing with people from other parts of the state and it also gives me the attitude that maybe I'm not so stupid after all. If I can join in on the conversations and people understand what I'm talking about then I'm not that stupid after all. Because that was the problem growing up. I always thought I was dumb (Michelle).

For most participants, being involved at some level with peer support activities, whether socially or more formally, was beneficial. Not only did it facilitate participants' interaction with others, it enabled them to take their lived experience and share the skills that they had developed with others. This in turn afforded them a greater confidence in their own recovery and a self confidence to engage with the community, apply for education and employment opportunities and, in John's words, 'do all these things that two years ago I just wouldn't have done'.

# 3.6 Support for the Supports?

One of the key issues that arises out of any discussion of natural support networks is that of the support available to, and required by, the supports themselves. One of the main natural supports identified by many of our participants was family. Most highlighted the pressure that can be faced by carers and identified that where a family member was providing care it was essential that they receive sufficient support and assistance from services in terms of education, practical assistance and time away. Matthew, for example, acknowledged that 'it is hard on carers, there's no doubt about that', and Lynette thought that they needed 'a lot more support'. Alan was also concerned that there was insufficient support for carers, particularly in rural and regional areas. His wife, who is his carer, told us that it took her seven months to get an appointment to see a psychologist because of the waiting list.

Those carers who did receive support were very appreciative. Darryn's wife found that having a support worker come to see her was 'really useful ... she really appreciated it'. Matthew's wife participates in an art group for families of people with a mental illness that she found useful, and John felt that his wife really valued participating in a program which has given her the opportunity to understand more about mental illness. But it was not just support that was identified as important. Respite and time away was also seen as important, particularly by John, who observed:

> sometimes your carer just needs to get rid of you for a few hours. If your carer can have some respite that's really a big thing and I know that [my wife's] had a lot of support that way through respite so that she can do things without having to worry about what I'm doing, am I okay ... She felt very hesitant at first to just go

out. As I was getting better and we were working through it together and she was helping me then I realised she needs some time out. I recommend to anybody who is caring for someone that they do take some time off or do get some carer's respite. It is there. It's a service so access it if you can.

Similarly, Matthew's wife commented that she really appreciated one service taking carers away for a couple of days, just to get away.

> If you are feeling that you're not coping they will make available a weekend away just for carers and I've had a trip to Strahan, a trip down the east coast.

Of the carers that we spoke with, many told us that if things became difficult for them they were often medicated or told that they were depressed. Those carers who were able to provide good ongoing support were those who recognised the need to take care of themselves and to have respite. As Matthew's wife told us:

> Matthew was in a really bad place and it was affecting me and I was told that I had depression. The doctor said you are depressed and wanted me to go on medication and I said no I wouldn't.

### Likewise, Alan's wife:

was basically told by my GP that I was both hysterical and suffering from depression and he wanted to put me on drugs. And my response to that was no I'm not actually depressed, I'm strung out and I'm responding to a situation where I think my husband is going to die any day cos he's constantly trying to kill himself. I'm not depressed. I can look out the window and tell you how fabulous the world is and take great joy from the small things. I'm not depressed. I'm just not coping. And he didn't know what to do with that.

# 3.7 In an Ideal World...

Finally, we were interested to hear from participants about what they thought was a good balance between natural supports and formal services and what in their view most helped in their recovery. Many participants found this difficult to answer as both forms of support were important for different reasons. John felt that the ideal balance was fifty-fifty. If he hadn't had his support services he wouldn't have been able to get where he was now. But without the support he received at home he wouldn't have accessed those services. So 'they both worked together to get me where I am'. Alan expressed a similar sentiment. He identified his wife as his main support. Without her he would have found it difficult to navigate his way through the formal service system. But the formal services were equally important in helping him to develop strategies and learn to live with his illness. Likewise, Lynette thought formal and natural supports 'exist in harmony with each other. You can't have one without the other.' Her worker's visit is 'incredibly important' and she 'couldn't do without it but at the same time I basically manage my own recovery'. And for Michael, while he felt that both formal services and natural support had been 'fairly ineffective', he did acknowledge that 'both were potentially very important'.

In answering this question participants also had many suggestions for improvement. Lynette, for example, suggested that the formal supports should work more closely with natural supports and encourage both the natural supports and the consumer to 'take action'. Allison thought that it was important for services to let people know what activities, services and social organisations were available, not just by putting notices up or telling people about them, but by being proactive in encouraging them to attend, and sometimes by accompanying them to the activity.

If people sit down and go through it with you and say look you are a bit interested in this how about you go along that makes another connection. It sort of has to be sitting down with you and saying look I think you'd benefit by going along, would you like me to come with you for the first time. Because often it is really hard that first time, just going. Silly isn't it. Incredibly hard just to go by yourself. So maybe go to the first workshop with them. Other participants commented that they didn't think there were enough activities available for people. Michelle felt that:

> there should be more group activities ... that people with mental health could do, cos ... it's only the same old ones over and over.

John was concerned about the range of age appropriate activities. Like Matthew, he valued projects such as the men's shed where 'you're doing something with your hands and you're creating something and creating relationships as well with the people you're working with'. However, he felt that:

> we need those sorts of services for older people. Then there's the young people. And then there's the group that are not youth but not completely old and then ... you've got the really old that are in the community, not in homes, but they're lonely, they've got nobody. So there's this gap ... How can the community help those people to get out and have a bit of a life rather than staring at four walls all day.

For Luke, who is 18, it was important for services to take you outside for some counselling sessions and engage in some kind of activity such as going for a walk.

> It doesn't need to be a bushwalk, it could just be round the block to get them started. Or hook them up with someone who can. Have a list of people who can help with those kinds of things. ... and just encouraging that. So I think that kind of communication and having a list of contacts and stuff and just being able to know that for depression being active is important so if you want to go for a walk or a run or jog or a bike ride or swimming or anything there's someone who can help with that. That would be a pretty important thing.

Darryn valued a 'support group that could just get together and have a coffee in a café somewhere'. And for Amanda and Gail the important thing was for there to be more resources and more people available when help is needed. Amanda was concerned that services were over-stretched due to lack of funding and Gail commented that:

what I fall for and what a lot of people fall for is that you walk into a doctor's surgery, psychologist, psychiatrist, and they tell you you can ring them anytime. But you can't because there is the 8 or 9 hours day that they're working. They're not available the other 13 hours when something's going to happen. Like the night mum died it was 9.00 pm when I was told. All I wanted to do was go and see my mum. I wanted somebody there who could be strong for me ... I needed somebody there for me and they aren't available.

A number of themes emerge from the above discussion. At a general level it is clear that people with mental illness want to feel part of a community. They want friends, they want to socialise, they want to contribute, they want reciprocal relationships with others. Social isolation, stigma and discrimination were identified as major barriers to this. Overcoming these barriers and feeling socially included was seen as both fundamental to recovery and hard work, and nearly all of the people we spoke with expressed that good networks of support were vital to the realisation of this outcome. For some of the people we spoke with natural supports were the most important component of their recovery. Likewise, formal services can be essential. And, importantly, formal services can have a key role to play in assisting people to access, build and maintain their natural supports. The challenge is in finding the most appropriate balance between the two.

# CHAPTER 4 – WHAT THE SERVICE PROVIDERS TOLD US

The community needs to change to be more inclusive and accepting of diversity and the way that people present. We don't seem to put enough emphasis on that, in trying to get the rest of the community to be more inclusive ... so that people don't get isolated in the first place ... What we do, we try to reconnect people to things. Our aim is to make ourselves redundant so that people are connected. That's our aim from day one. It isn't easy. It's not easy for people in our community (NGO worker).

As discussed in Chapter Three, a sense of community, social inclusion and relationships with others were identified by the participants in this research as essential to their recovery. They were also identified as key factors by the 19 frontline workers that we spoke to across Tasmania. These workers were drawn from six organisations statewide that provide mentoring, rehabilitation, recovery, residential, pathways and support programs for people with mental illness and their families. We talked to them about what they feel, in their experience, best helps the people they work with to live in recovery, the role of natural supports in this process and what their role is in assisting people to build, access and maintain these supports.



# 4.1 'I've never worked with anyone who's not socially isolated': How Effective Are Natural Supports?

In the last chapter participants identified natural supports as a vital resource in countering the social isolation which many felt was a barrier to their recovery. Nearly all of the workers we spoke with confirmed that social isolation and stigma were the main barriers to recovery. One worker reported, for example, that 'every single person I work with is socially isolated'. However, while some of the service providers we spoke with agreed that natural supports could play an important role in addressing this, it was not a universally accepted opinion. Some certainly highlighted the benefits of natural supports, such as family, friends, neighbourhood houses and libraries, acknowledging that they can be useful in helping to improve social connection. They told positive accounts of the people they work with engaging in activities with others with a shared interest such as going fishing, going to a yoga group or feeding the ducks at the park.

> People come up and say oh look at the ducks, what are you feeding them? It just happens naturally. Other people walk their dogs. They just come together and it's not enforced.

Engaging in these activities gave people opportunities to make new relationships and interact with a wide range of community members, not just those affected by mental illness. Workers also highlighted the benefits of participating in education and employment as an opportunity to be more socially connected.

> If it is a socially inclusive workplace and culture that can be a natural support ... even if they are just going there to talk about the footy or what they did on the weekend ... I've just enrolled someone in a TAFE course and it's not just because I'm thinking they'll pick up the skills and run with it, but that it would be a great way for them to be less isolated and to be out in that community.

And for one worker it was Maslow's Hierarchy of Needs<sup>3</sup> that he saw as the most important natural support, as without secure housing 'the rest of your life's going to be unstable' and without employment you lose a significant avenue of social connection. 'If you are excluded from those two your life is going to be impoverished.'

As a general observation, however, workers more commonly noted that people lacked natural supports. One worker reported, for example, that at least half of the people she worked with had no natural supports. Another noted that although often people do have friends and family:

> they're not connected into any particular social group and a lot of them are really struggling to get hooked up with anybody, particularly people who are their own age.

And others noted that many had a real 'yearning for friendships, someone to talk to and relate to'. This differs, to some extent, to what many of the people we spoke with told us. Many of them said that they did have good networks of support. As one worker pointed out, however, many of the people she worked with would not feel they could participate in this study. Several of the people she worked with identified as having no natural supports even though she was able to identify some, and 'there is no way they would sit down and have someone interview them. It would be too confronting.'

Workers also questioned whether all natural supports could be deemed to be 'supports'. They felt that it should not be assumed that all natural supports are a positive as many could actually be a significant risk factor for the people they work with and a potential barrier to their recovery. One worker reported that this was the case 'for half, for two thirds or even three quarters of our people'. Sometimes these supports may simply 'be a hindrance'. In supporting their loved ones, carers can sometimes become overbearing or controlling. Sometimes they may unwittingly stifle the development of other supports. One worker reported, for example, that sometimes people may only see or interact with one other support, such as their mother.

<sup>3</sup> Maslow's Hierarchy of Needs is a theory put forward in the 1940s by Abraham Maslow that creates a hierarchy of basic human needs – physiological, safety, belonging, esteem and self-actualisation. According to this theory an individual cannot satisfy higher levels needs until lower levels needs have been met. Housing and employment are two lower level needs. They become completely reliant on their mother to do anything ... and the mother struggles as well with always having to be there for them and they just end up feeling like a burden. So even though they've got someone that they are close to and that they can talk to, they feel like a burden because they don't have that broader network of people around.

Sometimes, however, it may be that the support is posing a considerable risk to a person's wellbeing. One worker reported, for example, that it was necessary to obtain a guardianship order for one of the people she worked with to protect him from undue pressure being exerted by a 'friend'. As another worker summarised:

> family and friends can be supportive but too often actually our people can be vulnerable to family and friends. So something does not necessarily exist as a natural support when it can be a risk factor for people in our community.

This same worker also commented on the risks of social media as a support.

Is the internet a useful support factor or is it a risk factor? It increases their social isolation. But it's like eating candy floss. It satisfies you a little bit but it's not really what they want. They actually want a flesh and blood person to be with.

Social media was one form of support about which workers were divided. Some thought that it could be a benefit, particularly where someone was not confident enough to engage in face-to-face conversation. In these situations, talking to people online with similar experiences may not be as confronting and it may be easier for someone to express themselves. As one worker highlighted, this can be beneficial as 'a stepping stone' until that person can 'find a real life group'. Facebook was also cited as beneficial as it enabled people to keep in touch with family and friends. One worker reported that it had been the catalyst for getting one of the people she works with linked into the local library, where he participated in a computer course to learn how to use Facebook. Others, however, thought that any potential benefit was outweighed by the risks.

It has got pros and cons. I have worked with someone and their only social outlet is through the net. The problem with that is that I feel that acts as a disincentive to have relationships in the real world. But from their perspective it's better than not being connected.

And for those who did not have that level of access it could be:

a double edged sword because people who are isolated and don't have access to that feel even more excluded. Like "all my friends and family are on Facebook, I don't know how to use a computer so no one remembers to call me anymore." There's a few people who have mentioned that sort of thing. So therefore they feel doubly excluded because they feel like they've been forgotten about.

# 4.2 Barriers to Accessing Natural Supports

According to the workers we spoke with it can often be very difficult to access natural supports. They identified five main reasons why this is the case: lack of opportunity, isolation, fear, lack of finances and service saturation. Lack of opportunity, in particular, was seen as a major barrier. Some workers talked about the challenges they experienced in finding opportunities for people to engage in. This was something that was particularly prevalent in rural areas. One worker reported that she was supporting a number of people who had relocated from the mainland to get a 'fresh start' but were now finding themselves isolated in regional areas, having left all of their natural supports behind, with very few support options.

> There is no transport, no access to services, they are finding it very difficult to fit in and are finding that this is a barrier to their recovery. They have removed themselves from all of those natural supports, people they have known all their lives that are perhaps more accepting of them. And I certainly have found that for those people the barrier of not having those natural supports impacts on their mental health quite severely.

And when there *are* opportunities it can be very difficult to access them, particularly for the first time. Workers reported that people were sometimes fearful of going somewhere alone for the first time. They may want to get out but they would rather do it with someone else.

Most people identify that they need to be drawn into organised things, eating with friends at the community centre, a choral group. But because they are the outsider coming into groups that are quite established that becomes a huge barrier.

Some service providers felt that they were limited in what they could do to address this issue because of restrictions on their time, the dangers of creating dependency and lack of flexibility. Workers with a full caseload may be able to accompany someone for the first one or two occasions but could not do so week after week. This is exacerbated further when events are not held within working hours.

> We have community BBQs where I live on Friday nights and I can't take anybody because it's outside of working hours. I have someone who wants to go to church but won't make that move on their own. And I can't go on a Sunday.

And if they did go more often there was the risk that they would:

become the person that they depend on. That I find is a huge barrier ... But it's then getting them to access it without me.

Lack of finances to fund activities was noted by many service providers as a barrier to accessing natural supports. By the time people had paid for necessities just finding the bus fare to be able to get to activities and events was difficult. As one worker said:

> The one thing that no one has mentioned so far is poverty. How many coffee shops are there in Lonnie? Plenty. But how many are there if you haven't got any money? It's outrageous now even for me. I begrudge paying four or five dollars for a coffee. Or if you don't have your own car how are you going to get out and enjoy the wonderful environment or supports that we have?

And service providers are not always in a position to be able to assist in these situations. They simply don't have the finances to be able to subsidise people taking part in activities that they cannot afford.

Finally, service saturation was also identified as an issue that prevented people from accessing other supports. One worker explained that sometimes there can be so many services used by a person that they become a barrier to the development of natural support networks. Their:

> natural response to everything that happens is to ring one of the services. And if they don't give them the answer they want they ring the next service and that can become a huge barrier to them actually looking outside of formalised services for what else they could do.

Another worker reflected that someone she worked with:

lived across the road from the shopping centre, busy road, heavy bags to carry, but no point driving. So she asked the local fish and chip shop across the road if she could leave half her groceries there. I thought that's amazing because they had agreed to it. But another service provider that she was working with thought that's too big a demand to make of somebody and you can't expect other people to do that, so now they take them shopping every week. They had good intentions, but I think that sometimes some of those creative options that people come up with are fantastic, instead of trying to make them fit in with what we would do.

# 4.3 How Can Formal Services Help?

If it is accepted that there is value in natural supports, the question that arises is how can formal services help people to build, access and maintain safe natural supports? Many workers identified that they did already work with a person's natural supports where possible.

> We've always tried to use and complement natural supports and one of the first things I think most of us ask our clients

is specifically what things do you do that are good for your mental health. And that gives you a perspective of their understanding of mental health. Have they got many natural supports and how much do they want natural supports.

As well as working with natural supports, however, providers also told us of how they build skills and confidence so that the people they work with can build their own network of supports. Many workers also highlighted the difficulties inherent in doing this. One worker thought that:

> at the start you can be a surrogate ... and help build their confidence so that they can even have conversations with people that are normal and comfortable and then ideally you want to shift towards them having those with other people in their lives.

Others, however, noted that they often became a crutch, a pseudo-natural support because of the lack of other natural supports.

After some time the person will look at you as being the person to meet their social needs. You are constantly trying to find ways to weave into the conversation that you are a paid worker and that you are only available in these hours. And that's quite difficult cos some people will latch on and think that they don't need to make other friends.

Countering this dependency and building individual capacity to access social activities and support outside the formal services framework is a challenge.

Workers reported a number of strategies for overcoming these issues and helping people to access available natural supports. One worker noted that building a good relationship was vital.

For me personally it's relationships. If you don't have that connection with the person and you aren't patient enough to build it then not a huge amount will happen because of you anyway.



Once this relationship was established workers could more easily link them into other non-mental health services such as libraries and 'all that stuff that's not a service-driven support'. Another felt that formal services are:

> like the scaffolding and we're just building up their self-worth a bit ... it's about trying to convey that they do deserve to access these supports in their life.

It is also about getting people to recognise that they actually do have natural supports and to identify what they are.

> I think one of the biggest challenges is getting people to actually recognise that they do have them, when they say they don't have anything. Then you start to unpack it and they have mum, and the church, and pop. So it's getting people to see that and it's working with people.

But equally important is reminding people that these natural supports are there. One worker told of someone she worked with who had a friend, but felt:

that they can't call this friend because "she won't want to hear from me cos I'm always feeling down". And I am building up and saying "I bet she would like to hear from you", and finding ways to get them to feel positive about themselves enough so that they can do that.

Another reported that she worked with someone who accessed the service because she felt she was socially isolated, however it turned out that she did have a lot of:

> natural supports around her and it's really just having someone there to remind her ... it's great that she's got friends and she takes herself to the movies and things like that. Maybe part of our role in some capacity is to keep reinforcing that.

Beyond this, the extent to which workers actually engaged or worked with natural supports was limited. The workers we spoke to reported that they did work with family and friends to improve relationship dynamics. They may help, for example, a parent to explain to their children or other family members about their mental health issue. Or sometimes they may intervene in situations to help someone become more independent from their family or disassociate themselves from a support that they may think is a risk. But they also reported that it is not always easy to work with these supports.

> I do have some people that don't want you to engage with their natural supports. And that's an interesting one. I'm still figuring that out as to how I can negotiate and work with that. But I think that within the program carers and family members and the natural community supports like churches and things have been fantastic at engaging with us if the person has been willing for that. But I don't think it is as simple as saying that we engage with them.

Engaging in mentoring and role modelling was also identified as important by workers. They emphasised that there was often a strong need to educate people and to role model how to engage with natural supports and participate and interact with others. Long-term isolation resulting from experiencing mental illness meant that many of the people they were working with did not have this level of skill. They hadn't had role models that taught them how to make friends or about what social norms are. As one worker expressed it:

It is that helping people to re-learn and I think part of what we do is that we have interaction and if we can build the bridge of trust to them, model to them what a good relationship or a good collaboration looks like then they can use those skills they've practiced in that safe space and they can begin to reconnect with the community. Once people build confidence, communication skills and resiliency they have the ability to explore their community and expand their support network.

One way in which services can help people to learn these skills is through organising social activities such as BBQs and other events. One worker reported that they had held such events every couple of months in the past and:

> clients would come along and it was a very popular fabulous event and then we got told that that's not recovery, you're doing it for them, that's not recovery at all. Then that stopped and our clients are constantly saying why can't we have BBQs.

Workers told us that these events were really appreciated by the people they worked with, who said that when they were there:

> they actually felt like part of a normal community. They were in the park having a BBQ with a group of people that they met with once a month, so it was like "oh what have you been up to, I've been doing this, how good was it when we caught up and went to the movies." They felt like their life was normal.

Part of this is also providing opportunities for social interaction and organising social activities that can then become self-sustaining. One worker told of how she achieved this.

I have a retreat this weekend (because we are working with a lot of the fire-affected victims). This is the third and last retreat for [them] and a few of those have made friends on the retreat. That was not intentional but it was really good that it happened because they continued the friendships.

Another gave a similar example.

We've actually developed a program ... that happens every Wednesday. It's just a group activity, which goes from 10.00-12.00 ... We'll have like art and craft, cooking ... We'll have guest speakers come, we'll go on barbecues, things like that. We now have up to 20 participants and five that come from other services, just from the local community. That's been really valuable as a natural support. The friendships that they've made and the connections that they've made with other people with the same issues has been really beneficial.

While there was some concern voiced about focusing on groups and activities that only involved people with mental illness, most workers emphasised the legitimacy of this level of peer support and thought it was okay for people to participate in a community of people with mental illness. It can make it easier for people to relate to each other, they 'don't feel like they are being judged', and they are able to support and encourage each other.

> You don't always have to be cheerful. You don't have to explain yourself. And I think the safety of being in that group and being able to be whoever you were on that day made that peer support happen.

It can help to build a community for people so that as they recover they are able to build their supports beyond mental health. As one service provider summarised:

> Well when we do group work the obvious spinoff is that people make friendships. People take that opportunity ... I think for the workers they need to be more aware of that and try to encourage people to make the most of that opportunity, or think they'd probably love to be invited to a BBQ.

# 4.4 An Inclusive Community?

One issue that was emphasised by a number of workers was that this is not just about natural supports and formal services. It is about how we, as a community, can be inclusive. As one worker explained, 'everyone needs a community. If people don't have that sense of community then they can get isolated.' However, workers reported that on the whole they did not find the wider community to be responsive or inclusive. One worker reported how their:

job is being in the community. And we all role play and no one knows who's the worker and who isn't. We do a lot of role playing practice and then we go to the library, go to the café and the staff are so rude and disrespectful. Another was working with a person who really wanted to do some volunteering but didn't feel comfortable or confident enough to do so. Workers felt that the onus was very much on the person with the illness to change to 'fit in' with the community, whereas they highlighted that it really should be the community that changes to be more inclusive.

One of the key themes here is education for family, friends, mainstream services, community resources and the wider community. As one worker stated, 'we've got to challenge the community and say listen what are we doing here' because, as he went on to point out:

most people's lives are going to be touched by mental health experiences. So you would have thought there was motivation to make things better.

For families and those who support people with mental illness there were calls for more education and support.

> As carers you don't get the education and support. And if you ask carers generally they actually don't know what to do, how to cope ... As a carer myself I feel that we need to do more to support carers because sometimes as carers we unwittingly disempower people. We worry about them because we can see that they are not getting the intervention that they need, which is also about skill. Managing mental health can be learnt and you can learn to do it better.

When it came to education of the wider community there were a number of suggestions about how to approach this. One example was to make greater use of resources such as libraries. One worker described how libraries could be a community hub, providing information on everything that was going on in the local community and, more importantly, being accessible, welcoming and inclusive to everyone who came in. Some workers reported that this was not always the case.

> For many participants if you want to find out about anything you go to the library. It really is a critical thing, so it

is disappointing that it's not welcoming because the people that we work with generally have low frustration tolerance. Making things accessible is critically important. If one person goes into the library and they get the brush off that might be it. It might take a really long time for them to have the confidence to try again. You say "why don't you try that" and they say "oh I tried it once and it didn't work out." You've only got one chance to make it.

Another suggestion was to have a whole of community approach that incorporated working with local councils to conduct community events that would be fun, informative and inclusive.

> What about having a whole of community approach? For example, on a Friday night the council could organise a BBQ and we could have talks about inclusivity. Imagine that. It would be great. Transport's the issue, we have to fix that ... But there is nothing stopping the council, or community members to just do it.

# 4.5 In an Ideal World...

Given the issues and concerns raised by workers, we asked them, in an ideal world, how they could best support people with mental illness. A number of workers were wary about the creation of a meta-narrative that prioritised natural supports. One worker expressed this concern as follows:

> I am a little concerned about the whole philosophy of natural supports. If we think about the wider context of where we are at ... in the de-institutionalisation era, basically what happened is that we closed down asylums, threw people back in the community and said there you go. And my concern about a meta-narrative of natural supports in people's lives is that there'll be too much expectation of natural supports ... I don't see natural supports as a substitute for service intervention.

He explained that while it might seem attractive to think that natural supports can take the lead so that the need for services is diminished, this would potentially result in a reversion to an approach where people with mental illness are isolated by their families and isolate themselves, so that 'they stay hidden in the community so the rest of the community is unaware. So we don't want to go back to those days.' This sentiment was expressed by other workers as making sure that an appropriate balance between formal and natural supports is maintained. This requires recognition that recovery can be 'two steps forward five steps back ten times before you get three steps forward', and that often a person's:

natural supports will come and go, but formal supports need to be able to walk alongside that and balance and help with understanding keeping balance. But it has to be a balancing act. It can't be one or the other. It can't be just this or just that. It has to be a balance because otherwise all you are doing is taking them out of one situation where they are not coping, and giving them support to keep them in another situation where they are not coping.

In helping to maintain this balance and provide services directed at achieving good outcomes for the people they worked with, the workers we spoke with had a number of priorities that they felt were important. These included flexibility in working with a person in terms of time and achieving outcomes, opportunities for mentoring and adopting a whole of community approach. Flexibility of time was a priority for many.

The hours that workers work tends to be 9-5 and I think if you are truly looking at breaking down barriers for people to access the community there needs to be times when you are actually more flexible. A lot of these community things happen in the evening. It is also about flexibility of approach. This may be having a seven day a week service, or it may be being creative in the way that workers build relationships because, as one worker emphasised, 'you can't really do anything with anyone I think until you have a reasonable connection with them'. Or it could involve being flexible with the way that workers interact with other community services.

> We have all taken a satellite area and we make ourselves know whatever is going on in the community. We go to the neighbourhood house on a regular basis, check out what is going on, make sure we know all of the people there, so that we've got actual face contacts when we're looking at somewhere to recommend that people join. I think that's really important, that services allow that time for their worker. Because it's not just ten minutes here and there. You need to visit a neighbourhood house maybe once a month for the next six months so that they trust you. That's really important when you are trying to link people into their services. They need to trust you. The recommendation is that workers often aren't given enough time to do networking with other agencies. We have found that really helpful.

But, as one worker pointed out, the problem with flexibility is resources. This was another area in which workers voiced the need for improvement, with many identifying the need for more funding for staff, time and greater ability to undertake activities.

As one worker stated, promoting recovery and wellbeing is about ensuring 'realistic sustainable intervention'. However, workers reported feeling pressured to be more targeted and outcomes focused and to provide these outcomes in tighter timeframes.

> One of the difficulties for service providers is that we are coming under pressure to become more "outcomes focused" and that is going to make it increasingly difficult to measure things like social participation ... It's definitely a narrative that's around. That we should not work with people for so long. Yet if we think about some of the people that we have had good outcomes with, I have had to work with them for three years and for the first two years it often doesn't seem like you're making progress and then in the third year they really flourish and fly away.

Other areas identified by service providers included improving opportunities for mentoring and staff development. While services engage in mentoring and role modelling themselves, one worker suggested that mainstream mentoring programs be expanded so that mentoring is not always provided by mental health services. They felt that there needed to be a wider understanding of mentoring that incorporated broader community involvement and would help people to develop sustaining friendships. When it comes to staff development and expertise, a few of the service providers we spoke with expressed a desire to engage in skill development in relation to understanding the role of, and working with, natural supports.

> I would be happy to put my hand up and say we need more training on how to properly engage families and carers ... The model of care that we are now working under is very much focused on natural supports and engaging the community ... And even though that's my role I would still put up my hand and say I need more training in it.

To summarise, essentially, what service providers told us is that both natural supports and formal services are important and that an holistic approach to a person's recovery is needed. As part of this, the role of community-based mental health services should be to help 'link and sustain participation' in the community.

# CONCLUSION

Perhaps unsurprisingly, a key finding of this research is that natural supports are an invaluable resource. This is true for everyone, not only people with mental illness.

We all rely on our family, friends, the environment, pets, sporting clubs, libraries, cafés, churches and so on to greater and lesser extents throughout our lives. They enhance our sense of belonging and quality of life.

As the World Health Organization states, good health, defined as 'a state of complete physical, mental and social well-being' (WHO 2006, p.1, emphasis added), is the foundation of the happiness and security of all people. So it should come as no surprise that natural supports and the feelings of engagement and wellbeing that come from accessing them were identified by the people who we spoke with in this research as having central importance to their recovery. And while many of us may frequently take these supports for granted, for people recovering from mental illness they often assume a far greater significance. They can literally be a life line. The people that we spoke with clearly stated that relationships, community inclusion and having something meaningful to do were fundamental to their recovery and essential in allowing them to live full and rewarding lives.

Clearly then, the absence of such supports will be acutely felt. While many of the people that we spoke with had good natural support networks and valued them highly, there were some who did not. They told us about the difficulties they had in accessing and maintaining these supports and about the barriers to inclusion they faced because of stigma and isolation. The service providers that we spoke with also reported that a majority of the people they work with lack natural supports. They also talked about how sometimes natural supports can be a risk factor for the people they work with because of their vulnerability and isolation. So what happens in situations such as these where there are no positive supports such as family or friends? It leaves the wider community. And from what we discovered from the people we talked to, people and places within the community can be a great support. Equally, however, they can sometimes be exclusive and unwelcoming.

The challenge in assisting people to identify, connect with and maintain a network of natural supports comes in effectively contextualising them at a local level for everyone involved. This would seem to be a reasonably simple concept, but not when considering individual circumstances, preferences and variations in the individual's and formal services' abilities to identify and foster these supports. Added to this are variations in service delivery modes and any limitations such as resourcing faced by these formal services.

At an individual level, any assistance given to people must reflect their preferences and what they think will work for them as far as natural supports go. It can't be dictated at a general level. Importantly, as well as the challenges already listed, assistance will always be dependent on the available resources within that person's community. While common themes were identified about natural supports, an homogenous experience was not.



When it comes to formal services the main point that needs to be made is that given the identified importance of natural supports in a person's recovery, proactive assistance to seek and foster these supports should be an integral part of any approach to working with people with mental illness in a community setting. These services also need to continue to offer activities that involve peer interaction. Peer support is a legitimate community of support that was highly valued by many of the people that we spoke with. They also highlighted the benefits of services actively facilitating opportunities for wider social interaction and connection. Simply offering activities is not always enough. Within this framework, however, formal services do need to remain mindful that it is not their role to replace, or stifle the development of, an individual's natural supports. Ideally, they need to work together, or:

> you end up having services that don't understand the need for people to be connected and then you end up having people who need to be connected but don't know how to (NGO worker).

Given the importance apportioned to natural supports by the people we spoke to, it would appear that their benefit may not just be in making people feel more positive and connected, but in reducing the severity of their mental health symptoms and the subsequent need for the intervention of formal services. If this is the case it would seem that the promotion of natural supports for people is not only a community imperative but also an economic one. As a community we need to ask ourselves how much we collectively want to help given that positive interactions with others can have an immediate effect on a person's confidence to interact and participate further. Given the prevalence of mental illness within our community, sooner or later supporting people experiencing it should be considered the business of mainstream organisations. And once people become familiar with mental illness and find out how to help those with it, the stigma surrounding mental illness will be reduced. In short, we need to explore further the nature of a truly inclusive community and the potential benefits it can bring to all of its citizens.

There is one final point that needs to be made in conclusion. That is, that the findings of this research should give hope to people with mental illness and to the natural supports and formal services working to support them. There is hope. Recovery is possible and though it remains for many an ongoing process, it can be positive. To refer once again back to Pete:

> I get really excited about recovery because I think it's fantastic. Each day it's a little bit better and sometimes it's good and sometimes it's bad. But you wake up in the morning and you still go, okay my goal is this. I have a problem with my mental health but I know how to get there. I've just got to get there.

Identifying, establishing and maintaining natural supports is important not only to this recovery, but to good health, happiness and security.

It is against this background and these conclusions that the following key findings and recommendations are put forward. They are influenced by the lived experience of people recovering from mental illness and by service providers who work closely with people with mental illness and have extensive experience of the mental health system. They are based on what this research and experience tell us about the importance of natural supports and present suggestions as to how best support people to connect with, build and maintain their natural supports.

## **Summary of Key Findings**

- 1. Recovery is a unique, personal and individual process.
- 2. Social inclusion and belonging are an essential component of recovery.
- 3. Social isolation continues to be a major barrier to recovery.
- 4. Natural supports are a vital and legitimate resource in facilitating social inclusion and recovery.
- 5. Natural supports include a wide range of resources, including family, friends, community organisations and the environment.
- 6. Some people find it hard to identify and access natural supports.
- 7. Formal services can assist in building natural supports.
- 8. Natural supports cannot be allowed to work alone. There needs to be support for these supports.
- 9. It is not really about one or the other. Natural supports and formal services need to work together to facilitate recovery.

### Recommendations

### Service Delivery

The people that we spoke with for this research told us that they value the role of formal services in supporting them to build their skills and confidence so that they can develop their own natural support networks beyond the formal service framework. Some, particularly those who felt they had no or few natural supports, also told us that they value the opportunities for social interaction provided by service providers. These sentiments were echoed by the service providers we spoke with. Role modelling, peer support and encouraging people to engage in social activity and interaction were identified by them as essential in helping the people they support to develop the skills and confidence to access natural supports. Greater integration between a person's existing natural supports and formal services was also identified by many as important. It is important here for services to be mindful of supporting a person to live beyond the formal service framework. While it is essential for services to be available when and where they are needed, it is equally important for a person to move away from this system when and if they can.

## Recommendation 1

That formal community-based mental health services prioritise and formalise their focus on natural supports.

While community-based mental health services may already work to 'link' people in with their family, friends or community, it is important that they identify them as a 'support' outside services. The language of 'natural supports' is important in focusing practice. Services need to engage more with this terminology. This may include creating opportunities for workers to develop a greater understanding of natural supports and their role in people's lives.

### Recommendation 2

That formal community-based mental health services ensure that they enquire about existing supports within a person's life, and the role that these supports play. This may include identifying whether there are family or friends who can be more formally involved in the service planning process.

# Recommendation 3

That formal community-based mental health services continue to provide opportunities for people with mental illness to build their confidence and motivation to engage in social interaction with others and to develop their own natural support networks beyond the formal service framework.

The emphasis here is on learning and building and developing skills. In this way, services can be a 'stepping stone' for people to live within their wider community, not just within the service community. In promoting and facilitating opportunities for social interaction it is important to provide a variety of opportunities and support to meet all needs and choices. This may include:

- Facilitating and creating opportunities for self-sustaining groups beyond services. In providing opportunities for social connection services need to be mindful of the risk of people 'getting stuck' in the formal service network.
- Exploring options to bring together people with common interests, not only those with mental illness. Services need to ensure that they are aware of existing opportunities within the community for people to engage with. They also need to be proactive and creative in their efforts to bring people together in order to foster greater interaction between people with mental illness and the community as a whole, and to promote activities that people want to engage in. This may include, for example, advertising an event or interest group within the whole community, not only the mental health community, or seeking out opportunities in which people have expressed a specific interest.
- Organising social events. Some people really appreciate this kind of opportunity to socialise with others. It remains important, however, that such opportunities do not replace other opportunities, and that organised events are intentional and promote learning and building and developing skills.
- Promotion of peer support that provides safe, non-threatening and supportive environments in which people can share with others who have had similar experiences to their own. Peer support was something valued by many of the people we spoke with.

## Federal and State Government

The people that we spoke to for this research told us that recovery is an individual and personal journey and that natural supports are an invaluable support in this recovery. They also told us that formal services play an important role in supporting them to build, connect with and maintain their natural supports. Services need to be able to work alongside individuals flexibly to support their recovery needs and help them to build their natural support networks beyond the formal service system. This is underpinned by national and state policy frameworks of recovery within which services operate. It is also important in light of current reviews at both a national and state level of mental health services.

### Recommendation 4

That Federal and State Government policy reflect the findings of this research and prioritise and recognise the role of natural supports as support for people living with mental illness.

## **Recommendation 5**

That Federal and State Governments ensure that programs retain the flexibility that services need to be able to facilitate and support a person's individual and unique recovery journey and support them to build positive natural support networks outside the formal service system.

## Supporting Natural Supports

This research clearly establishes that natural supports incorporate a diverse range of supports, including family, friends, churches, community centres, interest groups and so on. The research also clearly highlights that the people and organisations within the community that provide this support often need support themselves. The people that we spoke with agreed that it was essential that people who were supporting them have access to information and education about mental illness, and that they have opportunities for respite to allow them to care for themselves. They also told us that while there are some services which provide this support, there needs to be more and they need to be more accessible.

# Recommendation 6

That Federal and State Governments and service providers ensure the continuation and expansion of opportunities for education and information for friends and family supporting people with mental illness. It is important that these opportunities are relevant and are easily accessible.

### Recommendation 7

That Federal and State Governments and service providers ensure the continuation and expansion of 'respite' opportunities for friends and family supporting people with mental illness to have time for themselves.

### The Role of the Community

The people that we spoke with for this research clearly highlighted the importance of community as a support in helping them to build a good life. Both people living with mental illness and service providers told us that an inclusive and welcoming community can be the difference between feeling positive and hopeful and isolated and hopeless. Yet they also told us of places in our community - libraries, cafés, shops - which were not always welcoming or understanding of mental illness. There is a clear need for greater community understanding and awareness of issues surrounding mental illness and for the creation of spaces where people can feel welcomed. Much is being done to dissipate the fear people have of mental illness through current mental health awareness campaigns such as recent Mental Health Week activities and R U Okay. It is important, however, that these campaigns remain relevant and are ongoing, so that people are encouraged to talk about mental illness and assist those who suffer from it, and so that the stigma surrounding mental illness is reduced.

## Recommendation 8

That Federal and State Governments, service providers and local communities ensure that there is an ongoing community wide anti-stigma, education and awareness campaign at a national and local level designed to encourage people to talk about mental illness and be more aware of, and responsive to, others in their community.

This may include:

- Making community spaces more welcoming and places where people can access information about mental illness and about what is going on in their community.
- Conducting local community awareness activities such as information evenings and BBQs that involve and are welcoming of the whole community, not only people with mental illness.

# APPENDIX – HOW THE RESEARCH WAS CONDUCTED

This research explored the role of natural supports in recovery from mental illness. It draws on the experiences of both service users and service providers about social inclusion and recovery. It advances the work undertaken by Duff et al. (2013) by focusing on the value of natural supports in this recovery and the role of formal services in helping people to identify, engage with, stay connected with and build their natural supports.

# **Research Methods**

This research follows innovative qualitative methods adopted by recent research (Duff et al. 2013) in order to capture participants' experience of recovery, natural supports and social inclusion through a mix of photographic and interview methods. It entailed:

A review of the literature about how best to support recovery and social inclusion.

Semi-structured interviews with 17 people with mental illness. Interviews provided qualitative information about the experiences of people recovering from mental illness and what they find most helpful in their recovery. Participants were asked about how they identify, access, use and sustain their natural supports and whether these supports have enhanced their experience of social inclusion and recovery. Interviews also covered participants' views about the role of formal services in promoting access to natural supports, how this might be improved and the optimal balance between natural supports and formal services. Interviews aimed to capture the range and diversity of people's experiences by providing an opportunity to people to 'tell their story'. Each interview lasted for up to an hour. Participants were sourced from across the state through a range of community-based mental health services. They were invited to participate if they fitted the following criteria:

- current users, or recent ex-users, of community-based mental health services;
- aged over 18 years;
- resident in their local community for at least 12 months;
- from low income households entitled to a Health Care Card or Pension Concession Card; and
- in a well stage of their recovery.

Recruitment into the research was assisted by the positive relationships that participants had with these community-based mental health services.

Walking tours with participants where they described the people, places and things in their community which they find supportive. This included taking photographs of those supports. From this we mapped the range of natural supports accessed by participants. Walking tours lasted for between thirty minutes and one hour. In instances where participants were not able, or did not wish, to participate in a walking tour they met with the researcher and discussed what they would take photos of. They were also given the opportunity to take photos alone if they preferred. Participants were supplied with disposable cameras.

Three focus groups with service providers from community-based mental health services in each region of the state. Discussion focused on the strategies employed by services to help people identify, build, access and maintain their natural supports and to promote social inclusion. It also included discussion about the barriers and challenges of doing this as well as staff understandings of their role in relation to natural supports. Each focus group lasted up to two hours.

A research reference group of service providers, policy officers and a consumer representative provided advice and feedback on the research, assisted with identifying research participants, reviewed the final draft of the research report and provided advice and information on the development of recommendations.

## Table 1Profile of Participants

Tasmanian Region	Female	Male
South	7	1
North	1	2
North West	2	4
Total	10	7

### Table 2Age of Participants

Tasmanian Region	18-30	30-40	40-50	50-60	Over 60
South	2	-	1	3	1
North	1	-	-	2	-
North West	-	1	2	3	1
Total	3	1	3	8	2

In order to ensure that all participants felt safe to take part and that their confidentiality would be protected the following protocols were built into the research process:

- All participants received an information sheet about the research and were asked to sign a consent form.
- Interviews and walking tours were conducted at a time and place that was comfortable and convenient for the participant. Most interviews took place in the participants' homes. Focus groups took place at NGO premises.
- All interviews and focus group meetings were recorded and transcribed.
- All participants were reimbursed for their time and other expenses involved in participating in the research.
- Participants were able to withdraw from the research at any time without it having any impact on their access to services.
- The interviewer was able to refer participants to support services if that was required.

• Quotes from interviews and focus groups, and photographs taken by participants, have been used throughout this report to illustrate experiences and perspectives. However, all names and identifying details have been changed to protect people's privacy.

## Limitations of the Research

This was a qualitative piece of research based on interviews with a relatively small number of people. This has resulted in some limitations being placed on the research and its findings.

First, people were recruited into this research using purposive sampling. This means that the sample is selected in a systematic way based on what is known about the target population and the purpose of the study. The aim was for the sample to reflect, at least in key ways, characteristics of the target population. Emphasis was placed on including people who were using a diversity of different services, a range of ages, both men and women and from each of the three Tasmanian regions (see Tables 1 and 2). However, it is acknowledged that purposive sampling means that the study cannot claim to be truly representative of all people recovering from mental illness in Tasmania. Second, it is also acknowledged that using community-based mental health services to recruit participants means that people with mental illness who have no support from community services are excluded and that there is the potential for service providers to recruit only those consumers who are likely to provide a positive account of their own services.

Third, it is acknowledged that the people who are most willing to participate in research about natural supports are those most likely to identify as having positive natural supports and who feel confident in talking about their experiences. Those who feel they lack natural supports, or who lack confidence, are unlikely to have volunteered to engage in this research. The people who did participate in the research were, generally speaking, feeling well and many were actively involved in consumer representative and advocacy organisations. Many of them did have strong natural support networks.

Fourth, the research sample did not include any people from CALD or Aboriginal and Torres Strait Islander populations. Additional targeted research is required to explore the complex issues that are faced by these populations in relation to social inclusion and connectedness.

Finally, while not a limitation, participants going on a walking tour of their community and photographing their natural supports did present some difficulties. Not all participants were able to walk for any distance due to health and mobility issues. And for many their community and their natural supports were too widely dispersed to be within a walkable distance. Some people also chose not to take photographs either because they did not feel comfortable using a camera or because they simply didn't want to. In these instances the participant and the researcher met and discussed what constituted their community and what they would take photos of.

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