

welcome to the opening doors guide

This guide is intended to support community groups who want to include people with experience of mental illness in your club, programme, activity or facility.

Whether you are involved with the arts, health and well-being, sport, recreation, community education, culture or community service, *Opening Doors* can help you to be more inclusive.

This guide has been written by people with experience of mental illness and this term has been used throughout this booklet. Other common terms of use are mental health consumers, mental health service users, psychiatric survivors, tangata whaiora (people seeking wellness), people with psychiatric disability and tangata motuhake (special/unique people).

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**For more information about
Opening Doors please contact:**

Esther Bukholt

Community Recreation Advisor
Recreation Wellington
WELLINGTON CITY COUNCIL
Phone (04) 801 4144
esther.bukholt@wcc.govt.nz

Manager

KITES TRUST
PO Box 9392
Marion Square
Wellington
Phone (04) 384-3303
admin@kites.org.nz

Manager

MASH TRUST
PO Box 157
Palmerston North
Phone 0800 MASH TRUST
www.masstrust.org.nz

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why recreation?

“Recreation means having fun. It means relaxing. It means being sociable. It means challenging ourselves physically or mentally. All these things are especially important for people with experience of mental illness.”¹

People with experience of mental illness join in community activities for all the same reasons as everyone else. We like social interaction, being fit and healthy, competing, learning and having fun.

Did you know that 47% of New Zealanders will experience mental illness in their lifetime and many more will experience periods of stress or life events such as grief or loss that affect their wellbeing? Some of us may have one incident of mental illness in our lives; others may have ongoing mental health-related issues.

Did you know?

“In a study of 202 depressed adults, regular exercise worked as well as medication in improving symptoms of major depression.”²

What stops us coming along to your activities?

There are a number of barriers that may make it more difficult for us, as people with experience of mental illness, to join in recreation activities; we may have lost a great deal of self confidence, become isolated or be on a low income. There are many helpful things you can do to make it easier for us to join in your activities.

The biggest barrier to participation for us is often discrimination. Discrimination is when we get treated differently from another person in similar circumstances because of prejudice.

“In clubs, often the reaction is to treat me as though I am mentally impaired. You spend much of your time on the outside looking in. It is incredibly easy to be lonely and isolated in a crowd. I wish people could see me, not my illness.”³

¹ *The Blueprint Guide to Recreation and Psychiatric Disability*, Sane Australia, 2000, p.1

² Dr James A Blumenthal, *Understanding prognostic benefits of exercise and antidepressant therapy for persons with depression and heart disease: the UPBEAT study — rationale, design, and methodological issues*, North Carolina: Duke University Medical Centre, 2007, p.741

³ Debbie Peterson, Lynne Pere, Nancy Sheehan and Gael Surgenor, *Respect Costs Nothing: A survey of discrimination faced by people with experience of mental illness in Aotearoa New Zealand*, Auckland: Mental Health Foundation of New Zealand, 2004, p.62

⁴ Marilyn Stephens and Bridget Caird, *Countering stigma and discrimination: organisational policy guidelines for the public sector*, Wellington: Mental Health Foundation of New Zealand, 2000, p.6

“If we get it right for people with experience of mental illness, we get it right for everyone.”⁴

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knowing who we are and what we need

"Mental illness need not be mysterious if you make an effort to understand it."

What is mental illness? Mental illness is a term that refers to a group of illnesses that affect a person's mind. Mental illness can affect how a person thinks, talks, feels and behaves towards others and themselves.

Key things to remember about mental illness are:

- > people do recover
- > it is common, it could happen to you
- > everyone's experience is different
- > mental illness does not mean a person is intellectually impaired

"I like to think of myself as someone with experience of mental wellness who has had some hard times to deal with. Having a mental illness is not my whole story. Like everyone, I have good times and bad times."

Our wellness

"I don't tell people what my diagnosis is. Psychiatrists are still arguing amongst themselves what the labels mean. It's better to let people know what I'm like when I'm well and what I'm like if I get unwell."

Symptoms of mental illness

Some of us experience ongoing symptoms of mental illness; these can be many and varied.

Some examples are:

- > mood swings
- > very loud or very quiet behaviour
- > hearing voices
- > anxiety and agitation
- > paranoia and fixed thinking

These and other aspects of mental illness can affect how we are able to take part in your activities.

For more information about specific mental illnesses, see the fact sheets available from www.mentalhealth.org.nz



"When I turned up and started the [physical activity] games, the group was quite sceptical – possibly because of bad experiences they'd had with games and sport and recreation. So rather than me glossing over things or rushing on to the next game if they didn't like something, I just took those points of conflict and used them as discussion points to move forward. Talking things over and mastering the skill became the game and became more important than playing the game." Craig, Push Play Coordinator, Wellington City Council

Side effects of medication

Not everyone who experiences mental illness takes psychiatric medication. It is just one tool, one option that we may decide to take. If we are taking medications, like all medications, they may also have adverse side effects. **Side effects** that can influence how we join in community activities include, but are not limited to:

- > blurred vision
- > dehydration
- > dizziness and nausea
- > drowsiness, sedation or inability to sleep
- > excessively dry mouth
- > impatience or agitation
- > jerky or jiggling movements
- > loss of concentration or difficulty thinking
- > loss of coordination
- > rapid weight gain or loss
- > sweating

"The main thing I find with my medication is that I feel so terribly tired. It makes it so hard to get motivated."

Being safe and comfortable is largely a matter of common sense. But if you would like more specific information about medications, Medsafe has an excellent website www.medsafe.govt.nz.

Our physical health

Often people who have been diagnosed with mental illness also have physical health issues. This means we are more likely to have other ailments and illnesses, or that our health issues are less likely to be treated. For example, one study shows that certain psychotic drugs have been associated with up to 20% increase in the onset of diabetes.⁵

getting us there

"I have to really psych myself up to go out."

Reach out to us

To encourage us to join up to activities, think about visiting us in person – it will be easier for us if we've met you first. You could:

- > call and visit us at mental health organisations
 - let us know what you do and what activities you offer and find out how we can work together.
- Face-to-face contact is especially important for Maori and ethnic communities
- > offer us the chance to trial the activity for free
- > develop introductory sessions
- > let us bring a support person for free

"To me, if people care enough to come to my centre, I know they genuinely welcome people like me."

An up-to-date directory of mental health organisations in Wellington is available from the Kites Trust's website www.kites.org.nz or for a hard copy, you can contact the Trust on admin@kites.org.nz or **(04) 384 3303**.

Our journey

We will find it easier to get to your activity if:

- > we can easily get there by public transport
- > you include public transport information in your promotions and activities are coordinated around public transport timetables
- > you offer free car parking
- > you include information about access for people with disabilities

An excellent resource for planning journeys on public transport is available at www.metlink.org.nz.



"I went into ward 27 [inpatient Ward at Wellington Hospital] to do a physical activity session. I was really nervous and didn't know what to expect so I spoke to people in the same way they spoke to me, which made a really comfortable atmosphere. They were really fun, friendly people who wanted to play and talk. As shallow as it sounds, I learnt that they are just normal people!" Anna, Push Play Coordinator, Wellington City Council

How much will it cost?

Some of us are on low incomes and many of us have high medical bills. Flexible payment options, discounts and free services can make a real difference to us.

Flexible payment options to consider are:

- > lower rates for Community Service Card holders
- > concession cards for doing different courses at the same venue
- > offering people the chance to pay as they go
- > plenty of advance warning for special trips or activities that will involve extra costs to enable us to budget
- > offering flexible participation, eg if a person enrolls for a ten-week course and becomes unwell after five weeks, offer to make arrangements for them to finish the course at an alternative time

Promotions

We often have impaired concentration or focus, so it is easier for us to understand printed material if it:

- > includes symbols as well as words
- > uses simple, bold colours and large print
- > uses inclusive, positive and welcoming language

Signs and maps are best if they:

- > are simple and use symbols, as well as words
- > show where people are now and where they might want to go
- > have exits, quiet spaces and smoking areas clearly marked

keep us coming back

Welcoming us

The way you welcome us can be an important step to help us regain confidence in ourselves and our ability to try new things.

"The guy at the desk always smiles and says hi to me by name. He doesn't treat me like I'm invisible, even when there are other people around."

People

We really appreciate these qualities in tutors, leaders and coaches:

- > a willingness to engage and empathise with people, and not judge
- > the ability to work *with* us, rather than doing things *for* us

When communicating with us, remember there are many things that make it difficult for us to communicate. These might include:

- > voices that distract us
- > anxiety, eg about people judging us
- > impaired ability to concentrate and focus
- > having different kinds of life experiences than other people which makes it hard to join in

When you're communicating with us, we like it when you:

- > expect things to go well and accentuate the positive
- > treat us in the same way you treat everyone else in the group – ie like adults!
- > are clear about the group's protocols
- > are respectful

Practical things that leaders, tutors and coaches can do to make us feel welcome in activities include:

- > help people in a group get to know each other
- > keep to the same routines
- > encourage us without being too bossy
- > help us to take small steps
- > take the time to talk with us
- > let us set our own goals
- > ask us how we would like to be supported
- > be clear and fair with rules and boundaries – being inclusive does not mean that you can't be honest and direct with us about how our behaviour is affecting you
- > use positive language to describe people with experience of mental illness
- > learn more about mental health

Look for people within your group who have experience of mental illness. They may be your best role models and source of information.

PHOTO OPPOSITE: COURTESY OF JENNY SIAOSI OF FINELINE DESIGN AND PHOTOGRAPHY

"Just because we have a mental illness, please don't treat us like we're children or idiots. Our brains still work and we still have feelings."

"I find it hard to join in small talk. Often the first question is, 'What do you do for a living?' I haven't worked for over two years now but if you tell people the truth, that's all you become in their eyes: not a tall, blonde, mother-of-two, you just become the one who is mentally ill. So I avoid small talk as far as possible."

"Often people are shy and anxious about attending a group activity or event. Once they have turned up and discovered that they are accepted and that people make the effort to talk to them, they will always be keen to come back next time."

Dennis, Buddies (support group for people with experience of mental illness) Coordinator



"I remember one student who was real shy and real quiet and kept herself to herself. She wasn't really contributing to the group. We did a few things... that could have played a part in making her feel welcome and being part of the group. By the end of the week, she was laughing, smiling and joking and completely come out of her shell. Some of the exercises we did could have helped that. I think everybody felt really good about it going well for her and the part they played. Everybody got a huge buzz that she was really happy."

Joella, Teaching art to adults



Activities

Your activities will be more accessible to people with experience of mental illness if there is:

- > an emphasis on fun
- > an holistic approach, eg the social part of your activity may be the most valuable
- > choice
- > a range of activity options
- > flexibility, eg a mix of structured and unstructured activities

"I find the interaction and conversation good at my walking group, having a laugh and a giggle, and it's good to see others do the same."

Environment

Busy, crowded, bright spaces can be overwhelming for us, particularly if we are shy or experiencing side effects from medication. You can:

- > offer a place, such as a quiet room or separate area, and encourage us to take a breather when we need to and join back in at our own pace
- > include quieter activity sessions with fewer participants
- > offer private changing areas

"I get really panicky and uncomfortable getting changed out in the open in the changing rooms."



Smoking areas

It is estimated the smoking rate for people who use mental health services could be as high as 90%.⁶

Smoking is a reality for many of us and we need to know where the smoking areas are and when we can smoke. Information on quitting smoking could also be made available.

"I know I should give up smoking. I know it in my head, I know it in my heart, I know why. It's just too hard to give that up on top of everything else I'm dealing with - one day I will, but not now, not yet. I hate not knowing when and where I can smoke or being disapproved of for needing a smoke break."

Special aids

Like anyone else, we may have a physical disability and some of us also experience side effects of medication that cause rigidity of limbs and lack of coordination. Some of the aids and services your group provides for people with physical disabilities may be useful for us as well.

Water

Dehydration is a common side effect of medications. Provide free and easy access to drinking water at several places including the quiet space.

Our privacy

We understand it may be necessary for you to collect information from us when we enrol for an activity.

This can be easier for us if you:

- > explain what the information is for, and why you're collecting it
- > tell us who will see it and where it will be kept
- > give us a private space for completing forms

The information you collect is protected by the Privacy Act 1993 and the Health Information Privacy Code 1994. For more information, go to www.privacy.org.nz/privacy-act/

⁶ NZ Mental Health Update, Wellington: ASH, 2002

mental health first aid

People with experience of mental illness may sometimes get distressed or display unusual behaviour. You can make a positive difference. This is often just a matter of common sense, much like general first aid.

People experiencing mental distress may react in a variety of ways. This section will provide you with strategies and practical tips for dealing with difficult behaviour that may be related to a person's mental illness.

Prevention is better than a cure

Following all the guidelines in *Opening Doors* will make a big difference to our comfort and happiness. This definitely improves our mental health!

"If I'm talking to myself, you don't need to rush up and ask if I'm alright. But if I seem confused or distressed, you could offer to help me."

Unusual behaviour

This is behaviour that is outside of the ordinary but harmless.

Examples of unusual behaviour may include:

- > very loud or very quiet behaviour and speech
- > agitation
- > divulging lots of personal information

Some behaviour that may seem unusual might be symptoms of anxiety or effects of medication, eg pacing, staring and jiggling.

What to do:

- > remember behaviour that seems unusual does not necessarily mean that we need help
- > model acceptance of unusual behaviour in a respectful way
- > check privately that we're OK
- > consider whether it may be useful to acknowledge the unusual behaviour within the group



"An extreme mental health incident is very unlikely but it helps to be prepared. I work at Buddies and I take people out who are sometimes in extremely acute states but there has never been an extreme incident." Dennis, Buddies Coordinator

Disruptive behavior

This is behaviour that causes disruption but does not pose a physical threat.

Examples may include:

- > a participant wanting attention in an unreasonable manner
- > someone who appears very angry about some part of the activity and is raising their voice beyond acceptable levels
- > a participant who is constantly interrupting a tutor's instructions

What to do:

- > keep your 'cool'
- > talk to the person using a low, clear voice
- > remind participants of group protocols
- > bring everyone back to the purpose of your activity

Extreme behaviour

A distressed person may show extreme behaviour. Extreme behaviour is behaviour that is unexpected, difficult to understand and inappropriate.

Examples may include, but are not limited to:

- > a participant shouting abuse for no apparent reason
- > threatening behaviour
- > behaviour that could harm people, including the person concerned, or property

"I get sick of reading bad things in the paper. People need to know having a mental illness doesn't make you violent. They always link it up that way though. When did you ever read a newspaper article saying that a completely sane person did such and such?"

Did you know?

"Research has found that people with mental illness are more likely to be victimised by violence than they are to commit acts of violence."⁷

What to do:

Usually people who are showing extreme behaviour are distressed in some way. Overleaf are some guidelines for dealing with a distressed person.

How to talk with a distressed person:

- 1 **Approach the person gently.** Stay calm and confident. If you approach the situation expecting a positive result, you are more likely to get one.
- 2 **Make contact.** Use the person's name, introduce yourself and tell the person who you are. Try and find a quiet place where you can sit and talk. Focus only on the present.
- 3 **Acknowledge their feelings** or how you perceive them, eg "You seem distressed" or "You seem upset?"
- 4 **Ask** what they need or want, eg "How can I help you?"
- 5 **Set clear boundaries** and remind them of what we are here to do. Take charge, ie calmly tell them about what is required from them.
- 6 **Keep the person informed** of any action you intend to take. Be prepared to repeat yourself.
- 7 **Offer options** such as calling a support person, a quiet room for some time out, a coffee or a phone call to someone they trust.
- 8 **If the behaviour continues,** you may need to ask them to leave and set reasonable boundaries for the future. Remember symptoms are temporary. If someone's behaviour is a result of symptoms of a mental illness, the person will get well, so be careful about placing a complete ban on them. Instead, say something like, "Come back tomorrow/next week/when you're feeling better". You may need to help a person leave by calling a taxi or calling a support person.
- 9 **Violent behaviour** – if you feel there is a risk to the safety of the person involved, other people or yourself, call Capital and Coast DHB's Crisis Assessment and Treatment Team (CATT) on (04) 494 9169 or the Police on 111.

Follow up

After an incident, people in your group may benefit from an opportunity to talk over what happened. This will help people to express their feelings and learn about the situation.

Talk to the person involved about how you can work together and make a plan to prevent a similar incident in the future.

Organisations which may help you do this include Atareira (Supporting Families), the Wellington Mental Health Consumers' Union, Buddies, First Voices or the Oasis Network Inc. See the list of helpful organisations section at the back for more information and contact details.



finally

For those of us with experience of mental illness, being able to participate in a full range of recreation and activities has a huge impact on our lives and wellbeing, so thank you for making it this far.

"I'm still here after two and a half years and go out every Tuesday in all weathers! I've lost weight, become involved in lots of projects at the community centre and got to know lots of people... Walking helps you to clear your mind and face your problems. There's always someone out there that will befriend you and that you can talk to."

helpful organisations

Atareira
 (Mental health support for families and whanau)
 Offers support, education and advocacy
 Level 1
 274 Taranaki Street
 Wellington
Phone (04) 499 1049
 enquiries@atareira.org.nz

Crisis Assessment and Treatment Team Wellington (CATT)
 For psychiatric and alcohol or drug emergencies. Capital and Coast DHB's CATT team responds to crisis calls 24 hours, seven days a week
Phone (04) 494 9169

Te Kowhao
 Te Kowhao is a kaupapa Maori group who share their own unique perspective on mental illness. They offer hearing voices workshops or interactive speaking engagements
 213-215 Bedford St
 Cannons Creek
 Porirua
Phone (04) 237 9608
 manager@taaniwhaniwha.org.nz

Wellington City Council Recreation Advisor
 Recreation advice and support to organisations wanting to improve access to recreation opportunities for people with experience of mental illness
 Esther Bukholt
 Community Recreation Advisor
 Recreation Wellington
 Wellington City Council
 PO Box 2199
 Wellington
Phone (04) 801 4144
 esther.bukholt@wcc.govt.nz

Buddies
 Buddies is a peer support service run entirely by tangata whaiora for tangata whaiora and provides Buddies-run activities, visits to the inpatient unit at Wellington Hospital and offers one-on-one peer support to people experiencing social isolation. A "buddy" may be available to attend a recreation activity alongside a person who needs it.
 Level 6, NZEI House
 178 Willis St
 Wellington
Phone (04) 385 2104
 buddies.wn@paradise.net.nz

First Voices
 Provides education about mental illness by people with personal experience
 PO Box 27482
 Wellington
Phone (04) 385 2103
 firstvoices@caseconsulting.org.nz

Peer Support and Advocacy
 Offers advocacy, support and information for people with experience of mental illness and their families/whanau
 Oasis Network
 LOWER HUTT
 First floor, ISP Building
 14 Laings Road
 Lower Hutt
Phone (04) 566 1601
 oasisnetwork@xtra.co.nz

Warm line
 Peer support phone line for people who use mental health services
Phone 0800 200 207

Wellington Mental Health Consumers Union
 Offers advice and training courses
 Community House,
 level 2, 84 Willis St
 Wellington
Phone (04) 473 4433
 mail@wmhcu.org.nz

Kapiti Choices
 KAPITI
 19b Milne Drive
 Paraparaumu
Phone (04) 905 2110
 kapitichoices@paradise.net.nz

helpful websites

www.likeminds.org.nz
 Information about countering stigma and discrimination

www.medsafe.govt.nz
 Information about medications and their side effects

www.mhc.govt.nz
 The Mental Health Commission website

www.mentalhealth.org.nz
 A wide range of information and resources including fact sheets about mental illness

www.privacy.org.nz
 Information about privacy and personal information

www.sparc.org.nz
 The Sport & Recreation New Zealand website including information about the Push Play campaign

