

Case study 14: the Living Room

Since 1996 Recovery Innovations has run one of the two crisis centres in Phoenix, Arizona (population over 3 million). The service has two components – a relatively traditional locked sub-acute unit with eight beds, and a sub-acute eight-bed alternative called the Living Room. More than 500 people per month come to the centre, either voluntarily or brought by others (including 14% by the police). On arrival, they are met by a peer triage worker, so their first contact is with someone who has lived experience of mental illness. This creates a positive initial experience, which is especially important since this is the first contact with mental health services for 40% of attenders. The focus in the peer triage is on the individual's needs, and the peer may share some of their own story. The goal is to communicate a 'chronic message of hope'. The peer may then act as an advocate in the subsequent psychiatric assessment.

Following this process, the person may be discharged, admitted compulsorily to the locked unit, or admitted voluntarily to the Living Room. Only 6% of people brought by the police require compulsory admission. Criteria for staying in the Living Room include being able to take some responsibility for oneself, but guests often include people brought to the centre in handcuffs by the police.

The Living Room is staffed by three shifts of two peer support crisis specialists. They influence the environment, which is intended to be supportive to those in crisis – guests have full access to things such as food, drinks, television and videos, and plants and other decorations reduce the clinical feel of the service. Guests stay an average of two or three days, during which time they are left alone if wanted, and offered the chance to develop a recovery plan with the peer, or attend any of the daily groups. These optional groups are facilitated by peers and counsellors, and cover both recovery topics (e.g. goal-setting, low mood) and social activities. Given the proximity to Las Vegas, it may be no surprise that one group is a poker tournament. All groups take place with participants from the adjacent locked unit, and guests find themselves acting as peers for the locked unit in-patients – a beneficial opportunity to give something back and experience being valued. Mental health professionals provide input in the Living Room as needed, but none is based in the unit. Each guest is evaluated by a psychiatrist or nurse practitioner daily, and a treatment plan is developed by a counsellor or social worker.

A challenge has been how to respond when peer workers become unwell. The evolved practice is that they are, if wanted, admitted to the Living Room. The basis for this judgement is that in a recovery environment, everything is transparent – what is said to the person is consistent with what is recorded in notes.

A second challenge has been moving to non-use of force. Only two restraints or seclusions have ever been needed, and fewer than 1% of people are chemically sedated. One means of achieving this has been values-based, influenced by the presence of peers advocating non-coercive responses to conflict situations. A second route has been re-framing violent behaviour as a normal response to crisis – shouting, screaming and throwing things without damaging by-standers are all ways of coping with crisis, and not indicators of escalating hostility requiring intervention.

Further information: www.recoveryinnovations.org

Crisis is, though, about more than minimising the negative impact. The neglected aspect of crisis is that it can be a punctuation point in a person's life, through being a time either of acceptance or of developing a new trajectory in life. We turn now to how the positive benefits of crisis can be amplified.

Supporting identity in and through crisis

Relationships are of paramount importance during crisis⁵⁶². Although a detached relationship may be the only type of connection possible with the person, the development of a partnership relation as soon as possible is central. How is this done? Peers can be particularly skilled at making this kind of connection, as we illustrate in our next case study of a peer-led in-patient service run by Wellink (www.wellink.org.nz) – an organisation with 35% peer employees.

Key recovery-promoting features are attention to environment, trying to keep the person in their life, and a balancing of the need for safety and the opportunity that being in crisis presents to learn from the past and to re-orient future plans.

Case study 15: Key We Way

Key We Way^a is a four-bed peer-run residential alternative to an acute in-patient mental health unit. The service operates from a standard house overlooking a beautiful beach on Kapiti Coast, north-west of Wellington. No mental health professionals work in the service, which is instead staffed by 14 ‘recovery agents’ – people with their own histories of using mental health services. Two recovery agents work in the home between 8 a.m. and midnight, and one from midnight to 8 a.m.

People are generally referred by the acute services co-ordinator or local Community Mental Health Team, although self-referral is also welcomed. Admission decisions are made by the local District Health Board (DHB), an arrangement which works because of the mature relationship between Wellink and the DHB.

What happens during an admission?

The average length of stay is three weeks. Residents do ‘normal’ healing things – walk on the beach, make things, cook, go for a drive, go on group outings, watch comedy on TV, do some gardening. The aim of the house is to be a place which is conducive to recovery. As part of this, family members are actively encouraged to visit and to stay for meals.

During their stay, the intention is that residents work actively on future-focussed plans with the recovery agents. Initially plans are focussed on short-term goals, such as staying safe. Over time, the focus shifts to the development of a **personal plan** – a creative process to facilitate the individual re-connecting with their personal dreams and aspirations. It may be written, or can be a collage, an audio recording, a mind-map, a portfolio of work, a song – anything that re-connects the person with their life. The aim is to move past a maintenance model to focus on process – the generation of hope, motivation and ultimately healing. After discharge, residents are offered an outreach programme for up to 6 weeks, which may involve further work on their personal plan.

Who does the service work with?

Key We Way works with both detained and non-detained patients. The proportion of compulsorily detained people is small, because each resident must consent to going there, and because some people consent to voluntary admission to Key We Way although they would need to be compulsorily admitted to the local statutory service. The intention is that the choice of where to be admitted rests with the person, although in reality it is normally the clinician who decides.

Key We Way seems to be most valuable for people who are having their first experience of in-patient mental health services. It provides highly visible role models of a potential positive future – ‘here are people like me who are now working’. It is less suited for people who are not able to benefit from the peaceful environment (e.g. those who are loud and aggressive) or where absconding is an issue.

Case study 15: (cont.)**How is risk to self or others dealt with?**

For each admitted resident there is initially daily contact with the clinical team, which reduces in frequency over time. All residents have a clinical risk management and care plan, developed by the statutory clinical service. Recovery agents support and supervise the taking of medication, but do not dispense. If someone refuses their medication this is reported to the clinician.

All staff are trained in conflict de-escalation. If the person's behaviour becomes unmanageable, the recovery agent will call the police (if life is threatened) or the local Crisis Assessment Team to make an emergency assessment.

How does the service compare with a professional-led in-patient unit?

There are similarities with good acute in-patient units. For example, the importance of supervision is emphasised by the recovery agents, and there is a willingness in supervision to discuss both personal and professional challenges of the role. This includes the extent to which self-disclosure is helpful – the line is drawn more towards the self-disclosing end of the spectrum than is common in professional-led services, but there is still a line. Similarly, there is an emphasis on accountability. The service is accountable to Wellink, which in turn is accountable to the commissioning DHB. This accountability is monitored by a general management structure within Wellink.

One notable difference is in terminology. For example, residents may have favourites among the staff whom they want to focus on, or may want more self-disclosure from the recovery agent than is helpful, or may evoke strong emotional responses in the recovery agent. These challenges would be framed clinically in terms of 'maintaining boundaries', but in Key We Way the challenge is framed as 'developing sustainable relationships'. In supervision this involves discussion of the same boundary issues that would feature in a statutory setting, but the implicit communication in the language is more strategic and less defensive.

A second difference is in role markers. Indicators of status (i.e. who are the recovery agents and who are the residents) are notably absent in dress, talk and behaviour. The disclosure of difficulties by the recovery agents is validated, as is the giving of support by the resident to the recovery agent. Advice is offered to residents not from a position of professional expertise, but from lived experience – 'I don't know if this will help you, but when I went through this I found it worked to. . .'.⁵²¹

Further information: www.wellink.org.nz

Note:

⁵²¹The term 'Key We Way' is not a Māori word – it is a play on 'Kiwi' and also a pointer to the key being 'we'.

General strategies for supporting identity during crisis include:

- Keeping the person's normal life on the go: ensuring mail is collected, pets are fed, dependants cared for, bills paid, home secured, deliveries cancelled, etc.
- Maximising engagement from the person's support network, e.g. by abolishing visiting hours, and actively encouraging visitors and involving them in meals and other unit activities.
- Keeping life skills activated. If the person is able to cook for themselves, it is unhelpful for meals to be automatically provided. If the person enjoys reading or exercise (or any other form of personal medicine⁵²¹), these are important to encourage.
- Reinforcing an identity as a person from the first contact, rather than starting with illness-focussed admissions procedures. Talking with the person about their life, what

they want from admission, what they hope to do after, etc. Amplifying the positive parts of the person's identity.

- Supporting the person, over time, to reflect on and make sense of their crisis. How did it arise? What is good and bad about it? What learning does it contain? What plans or goals or supports or skills will the person need in the future?
- Using time strategically. Individualising the support to the needs of the individual. This may involve giving the person space to regroup, or individual counselling to support recovery processes, or access to artistic media and therapies to allow the expression of experience. A recovery-focussed crisis service does not have a compulsory programme of activities.

The challenge is to intervene in ways which keep the person in their life, or minimise their removal from it. This may require structural change to ways services work. For example, the involvement of police in the compulsory detention of people who have committed no crime is stigmatising and, for some, shame-provoking. This point is made by a head teacher who experienced a psychotic breakdown³⁰⁹: 'Looking back I'm glad they made me accept treatment . . . but if I needed to go to hospital why did they call the police to take me and not an ambulance . . . I still can't face my neighbours' (p. 6).

In closing our discussion of crisis services, we mention two other structural aspects. First, there are several residential alternative models to traditional in-patient care⁵⁶³, including short-stay crisis houses⁵⁶⁴, Soteria or recovery houses²⁵⁸, halfway hospitals⁵⁶⁵ and peer-run in-patient services (see Case studies 13 and 14). There are also several non-residential alternatives, including day hospitals⁵⁶⁶ and home treatment teams⁵⁶⁷. This last type of service involves increasing the level and type of support available to the person in a crisis through 24-hour intensive support, including medication, brief counselling, practical advice, information and other types of support for both the consumer and their informal carers. Unusually in comparison with the pattern of other service models, the findings from early evaluations⁵⁶⁸ have been essentially replicated in later investigations^{569;570}: home treatment is safe, effective, preferred by patients and suitable for up to 80% of people in crisis. What is less known is the extent to which they contribute to personal recovery. One home treatment team in New Zealand has actively embraced a recovery approach in its work¹²⁴. People using this service identified helpful aspects: practical help; being around; being available to talk; providing advice; providing information about mental illness; and hooking up with other useful services. Recovery-promoting operating practices included availability, flexibility, treating people as individuals, the team working well together, support to the family, establishing of strong relationships with the consumer, giving hope and encouragement about recovery, going the extra mile, including consumers and family members in decisions, and dealing sensitively with issues around choice and control.

Second, since compulsion involves control, democratisation of this power and promoting community responsibility for deviance is one approach to reducing the potential for abuse of this power. This has led some commentators to call for increased involvement of non-statutory sector services in decision-making about compulsion in mental health services²⁶. The extent to which this power is simply co-opted by other interest groups and whether there is sufficient community resource to take on this responsibility are questions which are amenable to evaluation.

We turn now to how to recognise, and evaluate the impact of, a recovery-focussed mental health service.

Recognising a recovery focus in mental health services

How can we recognise a recovery focus in mental health services? Which aspects of current practice should be amplified, and which discouraged? How should the effectiveness of mental health services be judged? This chapter addresses these questions.

A variety of quality indicators for a recovery-focussed mental health service are proposed in this chapter, along with an outcome evaluation strategy. These can be used as the focus of an audit cycle, especially using external⁵⁷¹ and user-led^{186;572} approaches. Or they can be the focus of routine outcome assessment^{545;573}, an established healthcare technology⁵⁷⁴. The overall aim is to develop the culture of a learning organisation – giving the organisation the information (sometimes called practice-based evidence⁵⁷⁵) necessary to reflect on its performance against stated values, and the desire and empowerment to tailor behaviour towards these values.

Quality standards

There is as yet no accreditation process to identify a recovery focus in services. This is unfortunate, because it allows any service to incorporate the term recovery into its name, irrespective of its actual approach. In the future it will be of benefit when an accreditation process emerges, although this will be challenging: needing to consider staff values, engagement with community services, process issues such as hope promotion, and so forth: challenging but not impossible, as the fidelity measure for consumer-operated services³⁷⁴ described in [Box 12.1](#) showed.

Quality standards are emerging – see Case study 25. For example, the Pillars of Recovery Service Audit Tool (PoRSAT) identifies six pillars of service development: Leadership, Person-centred and empowering care, Hope-inspiring relationships, Access and inclusion, Education and Research/Evaluation³¹⁵. The most widely used quality standards are the *Practice Guidelines for Recovery-Oriented Behavioral Health Care*, which cover eight domains^{571;576}:

1. Primacy of participation
2. Promoting access and engagement
3. Ensuring continuity of care
4. Employing strengths-based assessment
5. Offering individualised recovery planning
6. Functioning as a recovery guide
7. Community mapping, development and inclusion
8. Identifying and addressing barriers to recovery.

Another approach is to investigate the consumer–clinician relationship. The Recovery-Promoting Relationships Scale is a 24-item consumer-rated measure about their experience of the relationship with their provider⁵⁷⁷. It includes items such as *My provider helps me*

recognize my strengths, My provider helps me find meaning in living with a psychiatric condition, My provider encourages me to take chances and try things, My provider sees me as a person and not just a diagnosis, and My provider believes in me.

In the absence of universal quality standards, we now propose some litmus tests which indicate a focus on personal recovery.

Belief markers

Some beliefs in traditional and personal recovery-focussed services are compared in Table 22.1.

A recovery-focussed service has a balanced view about the impact of clinical models. It recognises that many consumers benefit from the traditional practices and values of mental health services. The problem is that not all consumers benefit, and some are harmed. So the orientation of the service is towards doing better over time. This creates a learning organisation culture, in which performance information is highly valued, and the twin characteristics of ambition and modesty are present.

Other beliefs become evident in behaviour. For example, if the consumer needs to ‘game’ to get their needs met (e.g. becoming abstinent before getting housing, or reporting no voices before being discharged), this may be because of unstated clinical assumptions that treatment needs to come before other types of help or support, or that illness-related needs should be met before meeting normal needs. The overarching behavioural marker is whether the person is treated as the professional would like to be treated. Housing provides an example. Some professionals would love to live with a group of other people from the same profession, and others would hate it. Few would be pleased if their request for housing was responded to with a requirement that they go on a course to learn to be a good tenant!

We turn now to the language of recovery.

Table 22.1 Beliefs in two types of mental health service

Belief in traditional mental health service	Belief in recovery-focussed mental health service
We already ‘do’ recovery	Recovery is a journey not a destination, and we are on the way, but have a long way to go
Recovery begins with recognising you have a mental illness	Recovery begins by reclaiming a sense of who you are
My job is to diagnose or formulate, then provide treatments or interventions for mental illness	My job is to support the person in their journey towards a more meaningful and enjoyable life
My primary approach to relating to consumers is as an expert	My primary approach to relating to consumers is as a coach or a mentor
I have a duty to intervene	I have some must-dos, but I employ several approaches to avoid my agendas dominating our work together
I decide when compulsory treatment is necessary	Approaches such as Advance Directives minimise the extent to which I decide when compulsion is necessary
Staff and consumers are fundamentally different – they have a mental illness, we do not	Staff and consumers are fundamentally similar – we are all trying to live a meaningful and enjoyable life
It is better not to be open if I have my own experience of mental health problems	Being open with other staff and clients about my own strengths and vulnerabilities is a positive asset

Discourse markers

There is no right way of talking about recovery. Language is constantly evolving, so any linguistic symbol (i.e. a word or phrase) attracts unintended meanings over time. For example, in New Zealand the term ‘peer’ is used for people who self-identify as having used mental health services, since the term ‘service user’ is seen by some as having negative connotations of being a ravenous consumer of resources. Similarly the term resilience is preferred to recovery by younger people, because it has fewer associations with illness.

To some extent, therefore, the language used is irrelevant. What matters is the core values, rather than the words an individual professional uses (which are influenced by profession, education, context, etc.). However, since language shapes how we see and construct the world, it is important to consider how language can encourage recovery, i.e. to use shorthands which foster rather than inhibit the recovery journey. Some general principles can be identified. For example, person-first language is helpful – talking about the person experiencing psychosis or the person with schizophrenia (or, even better, the person with a diagnosis of schizophrenia) rather than the schizophrenic or the schizophrenic patient serves to remind that diagnoses classify illnesses, not people⁶². Similarly, the avoidance of illness-saturated linguistic environments – in which the only visible part of the person is the mental illness part – is important, so language to describe strengths and aspirations is a necessary counter-balance to discourse around deficits and disabilities. In Table 22.2 some traditional clinical terms and more recovery-promoting alternatives are put forward. Because there is no single best language, the intention is not to identify right

Table 22.2 Discourse markers of a recovery-focussed mental health service

Clinical term	Problem	Potential alternative
Case management	<i>People are more than a case (of schizophrenia, depression etc.)</i>	Recovery support
Case presentation	<i>This creates an expectation that what needs presenting, and therefore what matters, is the illness part</i>	Recovery presentation
Has a diagnosis of. . .	<i>When used without any qualification this becomes reified – seen as a true thing instead of a professional construction</i>	Meets criteria for a diagnosis of. . .
Patient/consumer/peer, etc.	<i>Puts the person and their experiences into a socially defined category, instead of encouraging self-definition</i>	Ask the person how they want to be referred to
Treatment-resistant	<i>Locates the reason for not benefiting as in the person AND pejorative AND normally a misleading synonym for medication-resistant</i>	Not benefiting from our work with him/her
The treatment aims are. . .	<i>Treatment should be secondary to recovery goals, rather than an end in itself</i>	The recovery processes being supported are. . .
Maintaining boundaries	<i>Has implications of a fortress mentality, and needing to defend against harm from ‘the other’</i>	Creating sustainable relationships
Introducing as ‘I am Dr Smith’	<i>Positions the professional as high social status and imposes a clinical frame of reference which constrains the resulting discourse</i>	‘Please call me Sam or Dr Smith, as you prefer’
Maintenance, stabilisation	<i>Expecting no improvement is self-fulfilling AND pejorative</i>	Consolidating gains
Risk management	<i>Views all risks as to be avoided, so does not encourage personal growth</i>	Harmful risk and positive risk-taking

and wrong ways of talking. Rather, the aim is to make visible some embedded assumptions and to suggest one of many approaches to talking in ways which support recovery.

Other discourse markers which are harder to specify in concrete terms are being open to discussion of power and choice (and its limits), and having a meaningful concept in regular use of expert-by-experience.

Evaluating success

Assessing the outcome of mental health services is vital, for both external and internal reasons. Externally, the spending of tax-payers' money on mental health services rather than other demands can only be sustained long-term if there is evidence of value-for-money, and outcome evaluation provides the value data. Internally, a learning organisation requires regular feedback on its performance. How can we evaluate the impact of a mental health service in ways which promote a focus on recovery? The difficulty is summarised by Julie Repper and Rachel Perkins⁴:

Traditional yardsticks of success – the alleviation of symptoms and discharge from services – are replaced by questions about whether people are able to do the things that give their lives meaning and purpose, irrespective of whether their problems continue and whether or not they continue to need help and support.

(p. ix)

The challenge is to measure outcome in a way which is both aggregable and meaningful. Outcome data need to be aggregated across individuals in order to meet many of the information needs of modern society – at the team, service, programme, region and national planning levels. The problem from the consumer perspective with aggregation is loss of meaning (or granularity, as epidemiologists would put it). Collecting information primarily for aggregation purposes leads to a focus on quantitative rather than qualitative data and on average rather than individual ratings. Both of these features are experienced by many consumers as unhelpfully reductionist and associated with loss of individual identity.

Outcome evaluation should be based on a theoretical framework, and should measure what matters⁵⁷⁸. If not based on some form of theory, then it is incoherent. If not measuring what matters, then it becomes irrelevant. Having contributed to the evidence base on routine outcome assessment⁵⁴⁵, I know very well that although these are easy statements to make, they are remarkably complex to implement⁵⁷⁹. Whilst noting the implementation challenges, we finish this chapter with a specific (untested) proposal for an outcome evaluation approach.

The Personal Recovery Framework outlined in [Chapter 9](#) provides a theoretical basis for outcome assessment. It identifies two classes of outcome which matter (i.e. promote personal recovery): valued social roles which reinforce social identity, and individual goals which contribute to personal identity. Both classes of outcome have features which are relevant for outcome assessment.

Valued social roles include employee, partner, family member, friend, citizen, free (i.e. non-detained) person, etc. Their value is relatively invariant – most (but of course not all) people want a job, a relationship, contact with their family, some close friends, the ability to exercise citizenship rights such as voting, not to be held in hospital or prison, etc. Assessment tends to be quantitative and dichotomous (or at least on an ordinal scale, such as unemployed – voluntary work – part-time work – full-time work), and hence easy to aggregate with little loss of meaning. They can be measured using objective quality-of-life indicators. For example, the MHA Village uses ten observable outcome indicators:

1. Live in the most independent, least restrictive housing feasible in the local community
2. Engage in the highest level of work or productive activity appropriate to their abilities and experience
3. Create and maintain a support system consisting of friends, family and participation in community activities
4. Access an appropriate level of academic education or vocational training
5. Obtain an adequate income
6. Self-manage their illness and exert as much control as possible over both the day-to-day and long-term decisions which affect their lives
7. Access necessary physical health care and maintain the best possible physical health
8. Reduce or eliminate antisocial or criminal behaviour and thereby reduce or eliminate their contact with the criminal justice system
9. Reduce or eliminate the distress caused by their symptoms of mental illness
10. Reduce or eliminate the harmful effects of alcohol and substance abuse.

The primary advantage of this kind of outcome is that they are based on normal social values, and so avoid illness-focussed lowering of expectations (either by staff in an effort to be realistic or by patients with internalised stigmatising beliefs about what they can expect in life). Since most valued social roles occur outside the mental health system, they orient the actions of the service towards increasing integration and participation by the person into their social environment, rather than encouraging a decontextualised and service-focussed view of the person. Their primary disadvantage is their invariance – some people get along very well in life without friends, or a partner, or a job. Attempting to impose normal social roles has the potential to be oppressive. However, assessing outcome is intrinsically value-based. It is less oppressive to be concordant with a value of personhood – the person with mental illness is before all else a person⁴⁵³ – than with a value of clinical imperatives being more important.

Unlike valued social roles, individual goals differ from person to person. There is simply no way around this. Any evaluation of this aspect using predefined categories necessarily loses some of that uniqueness. No standardised measure will have items such as *Swim with dolphins*, *Breed snakes*, *Ride a motorbike*, or any of the other idiosyncratic goals individuals set and attain on their recovery journey (these are all real-life examples of recovery goals). Any attempt to squeeze personal identity into predefined boxes can be justifiably criticised for its loss of meaning. This does not of course mean that personal goals should not be included in outcome evaluation – they remain central, despite the difficulties in assessing individual goal attainment. Rather, as Robert McNamara put it, ‘The challenge is to make the important measurable, not the measurable important’¹⁶⁶.

There are developing technologies which allow for assessment of progress towards individualised goals. The most established approach is Goal Attainment Scaling, which involves the person identifying their own goals, along with markers of relative success or failure in attaining these goals⁵⁸⁰. The resulting data can be aggregated across individuals to give an indicator of the overall success of the service at helping people to reach personally valued goals. But the approach is time-consuming and complex. Another approach is to identify a list of standardised outcome measures covering a range of domains, and for the consumer to identify the most relevant outcome measure from the list⁵⁸¹. This allows a degree of tailoring of outcome to each individual, without the complexity involved in Goal Attainment Scaling. Data can be easily aggregated, but using a predefined list of outcome

measures reduces the extent to which assessment is individualised. The simplest approach is to periodically collect a dichotomous rating about whether each goal has been attained.

So an overall outcome evaluation strategy would measure two things: first, objective quality-of-life indicators, such as adequacy of housing, friendship, safety, employment, close relationships, etc.; second, progress towards personal goals. A mental health service which can show it is increasing the attainment of valued social roles and increasing the proportion of personally valued goals being met by people on its caseload is likely to be a recovery-focussed mental health service.

We have argued that recovery involves the development of valued social roles. This often involves the development of inter-dependency skills – we can't all be mechanics, but it helps to know how to access a mechanic if our car breaks down. It is to this wider world of social inclusion, or exclusion, which we now turn.

Improving social inclusion

We have discussed the creation and fostering of hope, meaning and personal responsibility primarily at the level of the individual, with a particular focus on how these processes can be supported by mental health services. However, there is an interaction between hope and opportunity⁴. If no person is an island, then recovery cannot happen just within the individual. Access to and experience of valued social roles is the lifeblood of well-being for most people. And yet mental illness is associated with disconnection from these normal social experiences of community integration which are so central to supporting and buttressing the processes of recovery.

In this chapter, we argue that a focus on available resources in the environment creates more opportunity than a focus on environmental barriers. This is not to argue that if we ignore societal stigma and discrimination, the adverse impact of these factors will simply be nullified. Rather, just as we argued in [Chapter 16](#) that an exclusive focus on the individual's deficits and dysfunction is unhelpful, it is recognising that individuals who are focussed on what they can do (the possible) rather than what they can't do (the impossible) are more likely to utilise available opportunities and to develop new opportunities.

Personal responsibility and social opportunity are the twin requirements for community integration. The individual needs to try to access the community, and the community needs to be accessible. These are not, of course, independent³³⁰: 'A central route to escaping this Catch-22 situation of needing to free oneself from the clutches of the illness in order to develop the capacities needed to free oneself from the clutches of the illness is for the person to reconstruct an effective sense of social agency in the midst of persistent symptoms and dysfunction' (p. 157). Social agency is the ability to view oneself as a person capable of choosing, initiating, doing and accomplishing things in the world. As described in [Chapter 18](#), agency is central for self-management skills and for the attainment of valued social roles. The development of social agency is a key recovery process, and is difficult where the person experiences discrimination. The New Zealand blueprint for mental health services states²⁹¹: 'One of the biggest barriers to recovery is discrimination. That is why stopping discrimination and championing respect, rights, and equality for people with mental illness is so important. It is as important as providing the best treatments or therapies' (p. 18).

To put this another way, Amartya Sen, who won the Nobel Prize for Economics in 1998, identifies the notion of substantial freedom, meaning that even where legally codified, freedom is effectively restrained when a lack of psychological, social and financial resources make it impossible to achieve goals and live a meaningful life⁵⁸². In relation to mental health, Faith Dickerson asks some simple but important questions⁵⁸³: 'How can one recover—in any sense of the term—in America in 2006 with a total monthly income of \$500, or while homeless, or with no health insurance?' (p. 647). Creating pathways back into mainstream society has direct benefits for identity, self-managing the mental illness, and

social role development³⁷³: ‘The more you get out, the better you feel . . . It just opened my eyes that there are other things to think about beside mental illness . . . [that] I could go places and have fun’ (p. 284).

Hopeful individuals can create opportunities. Changing environmental opportunities can engender hope. What does this person–environment interaction mean for mental health services? Comprehensive approaches to discrimination, including conceptual frameworks⁸⁶, impact^{4;584} and remedial strategies^{56;585}, have been considered elsewhere. In this chapter we will identify the contribution of three groups who can improve social inclusion: mental health professionals, consumers and governments.

Mental health professionals can improve social inclusion

Mental health services have not always focussed on promoting non-patient roles. The sociologist Erving Goffman identified how characteristics of other total institutions (e.g. military, jails) applied in mental institutions⁷¹, through processes such as institutional stripping – the systematic removal of identity markers from the person. The benign intent was to re-mould the individual into a more conforming or normal member of society, but this rehabilitative goal was found in practice to be outweighed for many individuals by the loss of a sense of self outside the institution. Institutionalisation leads to ex-military who can’t survive in civvy street, recidivism by released convicts needing the security of prison, and mental patients for whom the hospital becomes their home.

We are now in the post-institution era of mental health, where this phenomenon is more clearly recognised. That said, there is an episodic nature to institutions – I was recently taken aback when teaching to be asked by a medical student, ‘What’s so bad about institutions?’. It was a reasonable question from someone who had never seen a back ward, as the warehouse wards used to be called. My first experience in the psychiatric system was doing voluntary work at school, and visiting a hospital (now closed). I walked in to see a man sitting masturbating in the day room. I was greeted by the staff, who walked me past him with a ‘Never mind him – he’s always doing that’ comment. I was shown round, including the padded cell which contained a wild-eyed bound man, wriggling in a strait-jacket. I don’t need to ask the medical student’s question, but new generations will.

The historical role of services in segregation, described in [Chapter 7](#), means that the mental health system has been part of the problem. A new direction is needed if mental health services are to actively challenge the exclusion of people in the future, and instead to be part of the solution. What might this involve?

A central transition is to enlarge the focus of a clinician’s role, to being about more than treating individual patients. Treatment is of course part of the job, but so too is supporting people to exercise their full citizenship rights. Overly focussing on doing things at the individual level creates ghettos of mental illness, in which special services, housing and employment for people with mental illness create a parallel mental health universe – a virtual institution² – in which exposure to everyday, non-mental-illness-defined experiences is almost entirely absent. To be part of the community involves exercising full rights of citizenship, and obtaining and maintaining social capital: ‘people have a right to participate, as equal citizens, in all the opportunities available within the communities of their choice’⁴ (p. x). It is insufficient to simply be geographically in the community in invisible ghettos of dedicated day services and accommodation. Segregation and social exclusion follow from an exclusive focus on individual treatment.

The contribution of mental health services to promoting social inclusion is not primarily about where mental health service buildings and resources are situated. Indeed, there are

approaches that do not involve creating either real or virtual institutions. For example, the Fungrata Program in Bogota has no mental health centre – it works with homeless people with a mental illness by focussing on the development of natural supports and independence through work and rehabilitation⁵⁸⁶.

Rather, the contribution of mental health services to social inclusion comes from how the service works. A central orientation of mental health services needs to be towards keeping people in their own lives, rather than transplanting them into mental health settings which inevitably reinforce an illness identity. Organising around this vision is difficult. For example, mental health services in England spend £123m per year on day services, yet a review of success in implementing a social inclusion agenda concluded that change is ‘usually slow and difficult, with resistance being a common feature’⁵⁸⁷ (p. 5). In particular, the review noted that ‘User-run services appear to remain relatively uncommon, despite the prominence they are given in the commissioning guidance’ (p. 4).

Keeping people in their lives does not mean casting them adrift: community integration should not mean community isolation. There is a role for specialist services, both as pathways into mainstream community activities and, for some people, as an end in themselves. The point is that the orientation needs to be towards creating a conveyor belt out of the mental health system and into a socially valued life. The implication is that workers in the mental health system ‘need to move away from a perspective that considers “patients in our services” to one of serving people in their communities, enabling people to live the lives they wish to lead’⁴. This is underpinned by a fundamental re-orientation towards a view that⁵⁸⁸: ‘the failure of a person to display competence is not due to deficits within the person but rather to the failure of the social systems to provide or create opportunities to be displayed or acquired’ (p. 130). Employment provides a concrete example. It is a central part of recovery, not what happens after recovery. A key challenge is to avoid impoverished expectations⁵⁵: ‘Currently services aren’t geared towards you getting access to education, training, or employment, unless you want to do the three Fs: filth, food, and filing. These are your choices, you can be a cleaner, you can be a waitress, or you can file stuff. I’m too bright for that!’ (p. 10).

How do these low expectations arise? One reason is that a focus on clinical recovery involves cessation of normal expectations whilst the person gets back to normal: ‘Let’s think about work when you’re feeling better’. This is one way in which a focus on clinical recovery can be toxic to personal recovery – it fails to recognise that work is something that for many people creates and maintains wellness, rather than something to do once well⁵⁶: ‘I always get this remark that I should take it easy, I shouldn’t stress myself as if I’m a weakling, or maybe because of what has happened to me I can no longer do things that I used to do and I don’t like that. I want to feel like everybody else’ (p. 30).

A central insight of the recovery approach is that social agency and the attainment of valued social roles is not what happens *after* the person is better. Rather, it is for many people the vehicle of their recovery. This challenges many current practices. The person who wants to experience love is given social skills training. The person who wants a home must show they are abstinent from alcohol. The person who wants a pet must first prove they can be responsible. The person who wants to have some fun is put into a leisure group. The alternative, recovery-focussed orientation is to recognise that people learn from real experiences, and rise to real challenges. People experience love by being in social and work situations, and going on dates. People stay off alcohol because they prefer to keep their home. People rise to the challenge of looking after another being. People with mental illness have their own idea of fun, which is unlikely to be the same as everyone else’s in the leisure group.

Another reason for low expectations is the chain of reasoning that work is stressful, and stress exacerbates symptoms which in people with a mental illness leads to hospitalisation, so work causes hospitalisation. Of course work is often stressful, but it has real benefits: pay, a social network (often of people with no mental illness), a non-illness role, etc. Just as a focus on deficit during assessment leads to a biased view of the person, a focus on the difficulties associated with work reduces access to the potential benefits. As ever, there is no invariant solution to this balance, other than recognising that it is a balance. For some people, being asked to meet the demands of employment is setting the person up to fail. But for many others, providing supportive pathways into real work is a central contribution to recovery. The challenge is to avoid a bias towards low expectations, by holding a values-based assumption that normal social roles such as employment should be available to all. Efforts then more easily become focussed towards making attainment of those roles possible, rather than towards encouraging realistic (i.e. low) expectations in patients.

A third reason for pessimism is reality. Whilst employment rates among the general population and among most disability groups rose in the UK between 2000 and 2005, they fell from 14% to 10% among people with moderate to severe mental illness³⁰⁴. Societal and professional pessimism about the ability of people with mental illness to work can be internalised by consumers⁸⁶. This creates a vicious cycle, because internalised stigma prevents people from trying to obtain competitive employment⁵⁸⁹.

Focussing on employment should not of course ignore the work-related difficulties which people with mental illness can experience due to the illness, rather than due to a negative societal response. Problems with concentration, personal organisation skills, hygiene, motivation and so forth can all be direct consequences which reduce work ability. A rehabilitation approach is important. This couples a positive expectation of success with a focus on developing relevant skills using evidence-based practices and providing support to bridge the gap between current capacity and goals. In practice, this means that individualised approaches to supporting the transition into work are needed, which focus on allowing the person to build up their work muscles over time.

A body of research into approaches to supporting people into employment is emerging⁵⁶. The consistent message is that Individual Placement and Support (IPS) approaches which support the person to find and maintain mainstream employment are better than training the person in separate supported employment schemes in preparation for mainstream work. IPS is more effective – 50% get paid employment, compared with 20% in sheltered employment⁵⁹⁰. IPS also has indirect benefits, by directly challenging discriminatory recruitment and retention practices, and reducing the social distance between the general population and people with mental illness. Overall, the empirical finding is clear: the best preparation for work is work.

Mental health professionals can increase the access of service users to the valued social role of work by supporting the development of employment schemes⁵⁰⁶. The main evaluation of IPS initiatives has been in relation to people with long-term mental health problems, but the approach may be relevant early in an experience of mental illness. An initiative at ORYGEN Youth Health Service supports employment-seeking among young people.

Case study 16: IPS for young people

The Individual Placement and Support (IPS) initiative was aimed at young people experiencing their first episode of psychosis. The goal is to support people into work before the formation of a stable and enduring illness identity. The support provided by the employment

Case study 16: (cont.)

worker during their six-month involvement includes use of an online careers guidance tool to clarify employment goals, CV preparation, cold-calling and visiting potential employers, and interview and post-placement support.

A central feature is that the gap between expressing willingness to work and starting work-related behaviours is brief. The employment worker is co-located with the service, and can be driving to potential employers with the young person on the same day as the person is referred by the case manager. For example, a woman who expressed an interest in screen-printing was taken to meet professional screen-printers, to identify the pathway into and nature of the career. This led to her signing on for a college course. A further type of support occurs post-recruitment, when the employment worker can be contacted by the employer if they have any concerns. Finally, the employment worker can discuss with the young person regarding whether and what to disclose. For example, they may discuss whether to get into the job, perform well, and then disclose about their mental illness after a few months, with or without support from their employment worker.

The integration of the employment worker with the mental health service avoids the inter-agency duplication of assessment and bureaucratic procedures which locally led to a two-month delay before job-seeking support was offered by mainstream employment support services.

The employment worker who was specifically focussed on supporting young people into mainstream work has been subjected to randomised controlled trial evaluation^a. The only inclusion criterion for the trial was willingness to work – criteria such as ‘readiness for work’ or symptom status were specifically not used to select participants. Employment rates at the end of the trial were 10% in the control group who had access to the normal group programme (including vocationally oriented groups). By contrast, 65% of people in the intervention group were in work at the end of the study, having received additional input from the employment worker. Similarly, the end-of-trial proportions in either paid employment or vocational training were 30% in the control group and 85% in the intervention group.

Further information Eóin Killackey: eoim@unimelb.edu.au

Notes:

^aKillackey E, Jackson H, McGorry PD. Vocational intervention in first-episode psychosis: individual placement and support v. treatment as usual. *British Journal of Psychiatry* 2008; 193:114–120.

One specific work opportunity is within mental health services. These are often large employers – the National Health Service in the UK is the largest employer in Europe. However, health services have a history of poor recruitment and retention approaches to attracting people with declared mental illness to work for them⁴. (Of course, many people working in these services have an undisclosed history of mental illness.) This is a wasted opportunity, and reinforces stigmatising us-and-them beliefs in the work-force. Actively encouraging applications from people who have used mental health services for all posts, and positively discriminating between applicants with the same skill level in favour of people with a history of mental illness are two relevant approaches. They directly challenge⁵⁶: ‘the common tendency in human service organisations to see workers as either healthy and strong and the donors of care, or as weak and vulnerable recipients’ (p. 32).

If a single outcome measure had to be chosen to capture recovery, there would be a case to make that it should be employment status: not because of a value about economic productivity, but because work has so many associated benefits. This idea is captured in the notion of vocational recovery, defined as a level of vocational functioning after the onset

of a mental illness above specified thresholds of stability and degree of workforce participation⁵⁹¹. Developing an evidence base about vocational recovery is an important research focus. For example, a five-year longitudinal study involving 529 people in vocational recovery found 47% had continuous employment, 23% had interruptions each of less than six months during the five years, and 30% had fluctuating employment with interruptions of more than six months⁵⁹².

Moving beyond employment, a general approach to supporting recovery is to provide services outside the context of treatment. An alternative context is education. The social role of student is positively valued, and one in which diversity is more tolerated and valued. This is the approach taken in our next case study.

Case study 17: education for well-being

The Division of Recovery Services is part of the Center for Psychiatric Rehabilitation at Boston University. Since 1984 it has provided a service for people with psychiatric disabilities through an 'educational lens', based on adult learning principles.

People using the service are students rather than patients. The course is based on four non-negotiable, non-debatable values:

1. Hope – holding hope for the student until hope is internalised
2. Choice – working with rather than on the person
3. Self-determination – respect for personal decisions irrespective of the educator's opinion
4. Growth – the focus is on strengths, satisfaction, success and skills.

The resulting difference in relationship is profound – as one student contrasts it, 'In hospital they tend to limit our identity to an illness'.

Information about the service is disseminated through both clinical and community services, and people apply and register for courses. The attendance expectations (the term used in preference to 'rules') are made explicit, and currently 150 students are enrolled each year, with services provided by 26 educators (including over 50% consumer providers). There is a waiting list of 200 people. All courses are free to students, who receive a 'Recovery Scholarship' to the value of the course. This both normalises the educational process as costing money, gives students a sense of value and places students into the valued social role of scholarship recipient.

A wide range of courses are offered, including healthy lifestyle (Food education, Sexuality and intimacy, Supported physical activity), spiritual (Tai Chi, Mindful meditation, Laughter yoga), daily living skills (Computing, Personal organization, Stress hardiness) and mental illness specific (WRAP, Recovery workbook, Health management and recovery). For example, the Writing course involves students reading accounts of recovery, writing a response, writing their own story and then writing their 'future story' of where they will be in ten years time. The Community and Recovery course involves voluntary work. The Photovoice course involves people taking a photograph about an issue of importance to them in their recovery, learning to narrate it and then bringing the narrated picture to those who hold power over their lives to change their minds.

The service aims to promote role transition: from patient to student to peer provider teacher to mentor to colleague. A key focus is therefore on community integration, especially in relation to work. The *Training For The Future* programme involves full-time attendance at work-related (especially computing) courses for six months, followed by a six-month internship in local businesses.

Several principles have emerged from experience: autonomy (as opposed to paternalism); risk, success and failure (rather than compliance, compulsion and maintenance); disagreement is part of the growth process (so should not be pathologised or labelled); using

Case study 17: (cont.)

'readiness to change' as a means of developing motivation is more helpful than using perception of motivation to determine readiness for change; and 'dependency' is not a dirty word – people may need long-term support (despite the cultural value to the contrary).

Risk is dealt with using normal academic approaches, tailored to the needs of people with psychiatric disabilities: behavioural expectations are made explicit, university policies regarding smoking/drinking/violence are followed, and an information card records the student's emergency contact details along with elements from advance directives about their wishes for crisis response. Staff response to inappropriate behaviour is informed by frameworks from education, such as the LEAST approach: Leave it alone, Eyeball without confrontation, Attend to the problem (privately and directly), Strategise with the student about the skills and support needed to meet behavioural expectations, Take a break from the programme. No student has ever been permanently excluded.

Further information: Dori Hutchinson (dori@bu.edu)

An important feature of this case study is that over 60% of the programme staff have their own lived experience of mental illness.

We end with concrete suggestions for how mental health professionals and teams can improve social inclusion.

Suggestion 1. Spend resources differently

A common experience of workers in the mental health system is frustration – a sense that these ideas about social inclusion, employment and social roles are all well and good, but impossible to implement within the existing constraints. The constraints differ from country to country (e.g. mental health policy, reimbursement arrangements, financing, workforce skills), but the implication is always the same – we can't do it here. At the heart of this issue is the question of what the job of mental health services is. We have argued that its primary task is *not* to provide treatment (with the implication that any other activity is a luxury), but to support personal recovery. Our next case study is an example of a system that decided to spend its available resources differently.

Case study 18: the MHA Village approach to employment

The Mental Health America (MHA) Village in Los Angeles works with people with mental illness who are homeless, deinstitutionalised and recently released from prison. Their goal is to 'help people create a life not defined by the illness' – and to replace the identity of patient with a more meaningful role. Their expectation is that altering day-to-day experiences leads to new roles, shifts in identity and, ultimately, changed behaviours and outcomes. Hence exposure to the experience of working is a central strategy.

The Village integrates its clinical support services with its employment services. This provides the opportunity for skills deficits and support needs to be met by a clinical staff while the employment service offers the realistic, 'normal' expectations of employees: that they show up for work, do what's asked of them, serve customers, and 'leave their mental illness at the door'. When is someone ready to use the employment service? When the person wants to work (i.e. a client's clinical state is not a primary criterion).

The features of any work environment capitalised on by the Village include non-disabled expectations, a focus on ability (to produce, serve, etc.), real work for which the client is

needed, participation as part of a team rather than a target group, internal motivations to manage symptoms, tangible results and the opportunity to practise the role of a 'worker' repeatedly.

For people who are anxious about working, the Work-for-a-Day option offers the chance to work for one shift, with the immediate gratification of getting paid at the end of the shift. For people with little work experience, the Village runs in-house businesses including a café where people can work for up to nine months. Job seekers apply in writing, are interviewed, get hired and are paid standard wages. For people with criminal backgrounds or a weak work history, the Lease Labor option offers community employers the option of contracting with the Village (not the individual) to get the job done – the Village pays the worker the same day and bills the employer. For people who would feel more comfortable working with people they already know, group placements are found through a Village employment agency, which contracts with community employers (without disclosing about issues of mental illness). The agency provides quality assurance specialists who check on the person's progress and offer on-the-job support where necessary – a less stigmatising and disclosing approach than a 'job coach'. Other approaches include seasonal work, temporary labour (short-term community jobs where homelessness or proper identification is an issue) and, of course, competitive employment.

Even a failure at work is both normalising (most people have such experiences) and contributes to creating a life not defined by mental illness. The experience of working (even if the job only lasts a short time) contains seeds of growth. Village members learn which jobs they like or dislike, what behaviours work or don't work and which skills have yet to be mastered. It has proven far better for adults with mental illness to have tried and learned than to be denied the opportunity to fail and grow.

All of this probably sounds expensive. The Village describes it as a cost or allocation shifting. It is based on the view that 'you get what you pay for', a fiscal paradigm shift that requires an emphasis on spending money to promote wellness and recovery rather than promote stability and maintenance. This has practical financial consequences. The top three areas of expenditure are individualised case management (41%), work (25%) and community integration (12%)^a. By contrast, the top three expenditures in the traditional clinical services were acute hospitalisation (28%), long-term care (23%) and out-patient therapy (23%). Since hospitalisations and living in institutional residence are markedly reduced for members attending the Village^b, the money saved is re-invested in work-supporting services. The evidence suggests that the reduction at the Village of costly hospitalisation rates and long-term care is a direct result of services that emphasise well-being.

Further information: www.village-isa.org

Notes:

^aLewin-VHI I, Meisel J, Chandler D. *The Integrated Service Agency Model: A Summary Report to the California Department of Mental Health*. California: California Department of Mental Health; 1995.

^bChandler D, Meisel J, Hu T, McGowen M, Madison K. Client outcomes in a three-year controlled study of an integrated service agency model. *Psychiatric Services* 1996; 47:1337–1343.

Suggestion 2. Organise community-based events

One way in which the community can be influenced towards seeing mental illness as part of 'us' not 'them' (and consequently taking a level of ownership) is through exposure. For example, at the MHA Village there is an emphasis on activities which give back to the community. Staffing a water station for a marathon gave an opportunity for members and staff to dress up, have fun and literally give back to the local community. This has unexpected pay-offs – a 911 dispatcher who had several times responded to emergency calls for police assistance to the Village was for the first time able to humanise the organisation which she

had previously viewed as a problem group. A key role of mental health services is to create these positive community experiences. This both has benefits for consumers – giving back is an important human experience – and makes a positive impact on the community.

Suggestion 3. Educate employers about workplace accommodations

Workplace accommodations can involve People (focussing on interpersonal challenges), Places (focussing on where the work takes place), Things (focussing on equipment needed to do the job) or Activities (focussing on the work tasks). For people with physical disability, accommodation needs tend to relate to Places and Things. This is what employers are used to. In mental illness, People issues are often the central issue. Employers need educating about how these interpersonal needs can be tended to.

A key contribution from the clinician can be educating employers about their legal duties under relevant discrimination legislation and about reasonable workplace adjustments for people with mental illness, which might include⁵⁶:

- addressing concentration problems by having a quieter work place with fewer distractions rather than an open-plan office
- the need to have some time away from other workers
- enhanced supervision to give feedback and guidance on job performance
- allowing the use of headphones to block out distracting noise (including hearing voices)
- flexibility in working hours, e.g. to attend clinical appointments or work when less impaired by medication
- mentor scheme for on-site orientation and support
- the need to talk to a supporter (e.g. a job coach) during a lunch break
- clear job description for people who find ambiguity and uncertainty difficult
- prior discussion about how leave due to illness will be managed, e.g. allowing the use of accrued paid and unpaid leave
- relocation of marginal job functions which are disturbing to the individual.

These accommodations often come down simply to good supervision: motivating the worker; providing clear and constructive feedback on role performance; and in general supporting the person to do a good job. Anticipating common problems experienced by people with mental illness moving into the workplace is also helpful, such as tensions around disclosure, needing to prove themselves more than other workers, and being reluctant to take sick days due to mental illness. Developing collaborative relationships with local employers is an important contribution which can be made by expert mental health professionals to increasing employment opportunities.

Suggestion 4. Use group skills in community settings

Most mental health services contain staff with a high level of skill in running groups in a mental health context. This does not promote social inclusion. Since the group is only for people who have a mental illness, this inadvertently reinforces an identity defined by the mental illness. Providing an in-house response to a need does not support a service orientation towards keeping the person in their life by supporting them to do things for themselves, or to harness their own existing natural supports, or to develop new natural supports. Finally, whilst community adult education services have had to make their services accessible to people with other forms of disability, the existence of special groups for people with mental illness allows mainstream discrimination to continue.

An alternative approach is for mental health staff with skills in running groups to approach local mainstream adult education services, and co-facilitate groups with adult education specialists in community settings. The groups would be on the same range of social and therapeutic topics as those currently run in mental health services, but would be open to anyone. The advantages of this approach are that the adult education service gains skills in accommodating to the needs of people with mental illness, the consumer experiences being referred to a mainstream group, and the group is genuinely community-based, involving participants with and without mental illness.

Suggestion 5. Amplify the voice of the consumer in society

Negative media portrayals of people with mental illness are pervasive^{534;535}. Mental health professionals can directly address the absence of media stories involving people who have recovered from mental illness⁵⁹³ by:

- Encouraging and training peer support specialists to be the spokesperson for a team
- Developing local bureaux of speakers who have recovered from mental illness⁵⁶ (see Case study 3)
- Refusing a media request to give a professional perspective without the guaranteed inclusion of a consumer perspective.

The role of consumers in improving social inclusion

A key approach to promoting social inclusion is to support the development of consumer activism. This has many potential benefits. It can be a pathway to recovery for the individual. It can provide a model of authentic partnership. It challenges social and professional beliefs about what recovery means – having someone talking about their own experiences of recovery is a powerful antidote to prejudicial beliefs about what is possible for people with mental illness⁸⁶.

This can be hard for mental health professionals. We are more used to seeing service users as the problem than as the solution. Yet the power of people with lived experience to impact on other consumers, professionals and society may be greater than that of professionals.

Ingrid Ozols is an example of a consumer-activist involved in employment. Ingrid's recovery journey has led her to the belief that getting well involves taking responsibility, and requires vigilance on her part. She has developed many supports: a doctor who acts as a temporary crutch (i.e. genuinely supportive but only in the short term – the goal being worked towards is always standing unsupported); medication (which 'lifts the fog' so she can see colours, think logically and get out of bed); a supportive partner and friends with normal (i.e. not over-compensating) expectations; and regular use of a coach who provides the occasional 'kick on the shins'. Ingrid identifies that she needed to get over the self-stigma of discussing her own experiences, and now uses her own story as the basis for a business.

Because it relies on the courage and strength of one person, this approach may not be generalisable. But it does point to the importance of mental health services looking out for potential consumer activists among people on the caseload.

Case study 19: Mental Health at Work

Mental Health at Work (mhatwork®) is a company started by Ingrid Ozols which works with workplaces to help promote mental healthiness in their workforce. The aim of mhatwork® is to increase retention and reduce claims against the corporation for mismanagement of

Case study 19: (cont.)

employees with stress and mental health problems and create a supportive environment. The business model is explicitly commercial – mhatwork® is not a ‘worthy’ activity or a not-for-profit organisation, but a commercial entity making a financial case for its services. Corporations, including some household names in Australia, employ the services of mhatwork® for financial not charitable reasons.

The company’s emphasis is on promotion, prevention and early intervention, with the ultimate aim for the organisation to undergo a corporate culture change. To achieve this aim, mhatwork® consultants draw on their own lived experience of mental health problems (whether the experience has been direct or indirect) to model breaking the taboo about the topic. The goal is to teach employees and managers to become better at ‘looking out for each other’, through openness on the part of the employee and appropriate work-place accommodations on the part of the manager and employer. Methods used are varied:

- Individual consultation – for example, discussing with a manager how to work with employees in a way which is both emotionally supportive and meets legal and organisational responsibilities
- Workshops – 2–4-hour interactive workshops for 15–25 staff, based on adult learning principles. The content can cover topics such as recognising the signs and symptoms of potential mental health problems, how to manage and support them, values, balancing work and life, and building resilience to help plan ahead to avoid ‘going crook’
- Educational materials – books, poster, pamphlets, e-learning resources
- Identifying and supporting local champions to provide peer support within the corporation.

Because of the emotional demands of self-disclosure, mental health support within mhatwork® is prioritised, including opportunities to debrief after each training session, and viewing peer support as normal rather than the exception.

Further information: www.mhatwork.com.au

A concern sometimes expressed about supporting consumer activism is whether people remain defined by their illness, rather than their personhood. A reasonable balance may be supporting people to use their own experiences because that’s what they choose to do, rather than because that’s all they are able to do. Many people who use their own history of using mental health services to develop a work role could clearly also prosper in other areas. However, there is no empirical evidence about what predicts whether becoming a consumer-activist is helpful or hindering of personal recovery. A consistent strategy is therefore to note the issue with the consumer and to support them to take responsibility for their own decisions.

The role of governments in improving social inclusion

Social inclusion can also be increased through interventions at local and national levels. A comprehensive range of interventions have been proposed by Graham Thornicroft^{56;86}, some of which are shown in Box 23.1.

Reducing stigmatising public attitudes will benefit people experiencing mental illness for the first time, since appropriate support-seeking in young people is hindered by low levels of information and negative images of mental illness⁵⁹⁴. It will also benefit people with ongoing difficulties, as a non-discriminating society is necessary if people with mental illness are to exercise their full rights of citizenship.

Box 23.1 Strategies to reduce discrimination**At the level of individuals and their families**

- Develop new ways to offer diagnoses
- Actively provide factual information against popular myths
- Develop and rehearse accounts of mental illness experiences which do not alienate other people

At the local level

- Commission supported work schemes
- Increase the availability of psychological treatments
- Health and social care employers give recognition to 'expertise by experience' through positive support in recruitment and staff management practices
- Ensure people with mental illness and employers are properly informed of their rights and obligations
- Provide accurate data on mental illness recovery rates to mental health practitioners and service users and carers
- Support greater service user involvement in local speakers' bureaux

At the national level

- Promote a social model of disability which refers to human rights, social inclusion and citizenship
- Promote service user-defined outcomes
- Audit compliance with codes of good practice in providing insurance

The best way to reduce stigma is not to focus on mental illness as a medical disorder. International research consistently shows that biological or biogenetic attributions are associated with a perception of *higher* likelihood of impulsivity, unpredictability and dangerousness in the minds of the public⁶³. This may be because the public equate biogenetic models with being deep and unchangeable, and therefore more 'other'. Nonetheless, mental health literacy campaigns often aim to communicate a message that mental illness is an illness like any other. One reason why this approach has been popular within mental health is suggested by Pat Bracken and Phil Thomas²⁶: 'Psychiatrists have generally been keen to downplay the differences between their work and that of their medical colleagues . . . However, patients (and the public) are well aware that a diagnosis such as diabetes does not lead to compulsory detention in hospital, whereas the label schizophrenia is a major risk factor for this' (pp. 8–9).

Although some commentators call for a closer link between mental illness and chronic disease models⁵⁹⁵, the epidemiological data on recovery rates reviewed in [Chapter 3](#) suggest that such a linkage is not empirically justified. Broadly one third of people recover without any help from mental health services. This group, invisible to mental health services, become apparent in population surveys⁵⁹⁶. Even those who use mental health services can experience clinical recovery from severe mental illness. As Daniel Fisher (psychiatrist and co-director of the National Empowerment Center) put it⁵⁹⁷: 'I have recovered from schizophrenia. If that statement surprises you – if you think schizophrenia is a lifelong brain disease that cannot be escaped – you have been misled by a cultural misapprehension that needlessly imprisons millions under the label of mental illnesses.'

The more effective approach to reducing stigma is contact with people with a mental illness⁵⁸⁵, where the person moderately disconfirms the negative stereotype. If they are

consistent with the stereotype then it is reinforced, whereas if they are too different then they can be dismissed as an exception⁵⁹⁸. The contact needs to involve the same status and goals for the different groups, be collaborative rather than competitive and have senior managerial support⁵⁹⁹.

Unfortunately, stigma is also found within mental health services. A good review of the available evidence about attitudes of mental health professionals is provided by Beate Schulze, who concludes⁷⁰: 'In sum, findings indicate that, while mental health providers are well informed about mental illness, they nevertheless do not always hold positive opinions about the conditions and the people they treat.'

We have already identified working alongside peer support specialists and seeing people in recovery as well as in crisis as approaches to reducing stigmatising clinician beliefs. Another approach is to develop new ways of talking about constructs traditionally referred to as dichotomous and discontinuous (e.g. schizophrenia, insight, responsibility, capacity), perhaps with terms such as 'a touch of schizophrenia' and 'partial capacity'. Of course for some purposes it is necessary to use a binary classification, but since the experience of even apparently discontinuous phenomena such as psychotic symptoms proves to be much more common in the general population than previously thought^{98;99;600}, language emphasising difference is neither empirically supported nor helpful in relation to stigma.

Turning to attitudes of the wider public, stigmatising beliefs have practical consequences. For example, the Burdekin Inquiry in Australia identified widespread systemic discrimination in relation to mental illness, with under-funding especially in relation to accommodation, employment and crisis care⁶⁰¹. What can be done about it?

In New Zealand, the inquiry by Judge Ken Mason in 1996 highlighted the negative way mental illness is viewed in society⁶⁰². This led to an anti-stigma campaign, which is described in our next case study.

The aim in [Section 3](#) has been to provide resources to crystallise and catalyse movement towards a recovery focus in mental health services. In [Section 4](#), we identify some of the concerns this may raise, and concrete actions with which to start.

Case study 20: Like Minds, Like Mine campaign

Like Minds, Like Mine is a national anti-stigma campaign run by the New Zealand Ministry of Health. It has three levels of intended impact⁷:

1. Societal – a nation that values and includes all people with experience of mental illness
2. Organisational – all organisations have policies and practices to ensure people with experiences of mental illness are not discriminated against
3. Individual – people with experiences of mental illness have the same opportunities as everyone else to participate in society and in the everyday lives of their communities and whānau.

It supports three actions:

1. Providing opportunities for contact with people with experience of mental illness
2. Promoting rights and challenging organisations, communities and individuals not to discriminate
3. Delivering evidence-based education and training.

The most visible intervention is a rolling series of national television and radio advertisements. The content of the advertisements was deliberately non-clinical in its focus, and was influenced by the family orientation of Māori / Pacific Islander cultures, who make up 25% of the New Zealand population. In these traditions, mental ill-health is located in the family

Case study 20: (cont.)

rather than the individual, and so clinical models of understanding are less culturally consonant. The key focus in the adverts was on raising visibility of, and reducing social distance from, mental illness.

Adverts featured famous and non-celebrity New Zealanders who have experienced mental illness. They included first-person accounts of what the experience was like and what helped or didn't help, and family, friends and employers talking about the person as an individual (rather than as a mental patient). For example, rugby player John Kirwan talked with his friend Michael Jones^b:

KIRWAN: I was clinically depressed, but I like to call it freaking out, because depression is such a word that people say, 'Snap out of it.' . . . What gets you through? Love, family, communication's a big one. You've got to talk it through. It's terrible when you're in there. But it's no big deal, it's pretty normal.

JONES: I personally noted, as a close mate, that I felt really guilty that I didn't recognise it . . . He went through something and he was prepared to face up to that demon, and that took guts and that took courage. You know, I'll always respect him and admire him and love him for that. (p. 195)

The tag-lines for the adverts are 'Don't judge a book by its cover', 'Are you prepared to judge?', 'Know me before you judge me' and 'The biggest barrier to recovery is discrimination'.

There have been many other initiatives. The programme is predominantly led, driven and delivered by people with experience of mental illness. In Capital and Coast District Health Board, the Mental Health Foundation of New Zealand (a national non-governmental organisation) ran a series of workshops for local communities. A Māori-specific resource to address stigma and discrimination has been developed. Research into addressing internalised stigma is under way.

Evaluation has been central to the campaign. The proportion of positive media portrayals of mental illness rose from 5.7% in 1994 to 11.1% in 2004^c. Tracking surveys of community attitudes to mental illness show improved public views about mental illness^d. This has concrete benefits. In a survey of 266 people with experience of mental illness, more than half reported reduced stigma and discrimination from family, mental health services and the public^e.

The success of the campaign is shown by its extension to 2013.

Further information: www.likeminds.org.nz

Notes:

^aMinistry of Health. *Like Minds, Like Mine National Plan 2007–2013: Programme to Counter Stigma and Discrimination Associated with Mental Illness*. Wellington: Ministry of Health; 2007.

^bMental Health Commission. *Te Haerenga mo te Whakaoranga 1996–2006. The Journey of Recovery for the New Zealand Mental Health Sector*. Wellington: Mental Health Commission; 2007.

^cMental Health Commission. *Discriminating Times? A re-survey of New Zealand print media reporting on mental health*. Wellington: Mental Health Commission; 2005.

^dVaughan G, Hansen C. 'Like Minds, Like Mine': a New Zealand project to counter the stigma and discrimination associated with mental illness. *Australasian Psychiatry* 2004; 12:113–117.

^eBall J. *What's been happening? A summary of highlights, activity and progress on Like Minds, Like Mine 2003–2006*. Wellington: Quigley and Watts Ltd; 2006.

Challenges

Concerns held by clinicians

In this chapter some of the many potential questions and concerns raised by clinicians about recovery are identified and addressed. This and the next chapter (which relates to concerns held by consumers) are written as questions or objections with suggested responses. This format will facilitate their use when making the case for a focus on personal recovery.

To aid readability there is a deliberately minimal use of citations, balanced by references to earlier chapters where the relevant theme was explored in more depth. Some of the answers draw from published sources^{603;604}, and others are personal views.

Isn't the recovery movement simply antipsychiatry by another name?

No. The original antipsychiatry movement of the 1960s emerged from within psychiatry. The recovery movement has emerged from the individual and collective voice of people who have used mental health services (see [Chapter 3](#)). It has an overlap with antipsychiatry in some aims – such as a challenge to the right to impose an explanatory model on experience and an awareness of (and wariness about) professional power – but aims such as giving primacy to the priorities of the individual and the importance of high-quality mental health services are distinct. Indeed, although there has been a recent strengthening of the alignment⁶⁰⁵, the antipsychiatry movement was criticised by early consumer activists as 'largely an intellectual exercise of academics'⁶⁰⁶.

There's nothing new here – we do this already

It is certainly true that some of the values embedded in a recovery approach have featured previously in the history of mental health services, such as Tukes's moral treatment emphasising respect and dignity in nineteenth-century asylums, and the development of social psychiatry with its focus on the social context in the 1950s and 1960s. It is also true that many individual clinicians are highly skilled at supporting people to self-manage, develop support networks, develop a positive personal identity and work towards valued social roles.

However, systems have emergent properties. In [Chapter 22](#) we considered some of the attitudinal, discourse and behavioural markers which characterise a focus on recovery. For services which exhibit those characteristics, the challenge may be communicating that practice to others. For services which do not yet exhibit those pro-recovery markers, it may be helpful to start with a recognition that there is a journey to make.

Recovery means cure – anything else is just twisting the meaning

I agree. The term is not ideal, partly because it places the discourse in an illness frame, and partly because the everyday meaning of recovery is indeed cure. As Roberts and Wolfson put it, 'In the context of a progressive dementia, for example, the victory over disease

implied by “recovery” can seem a hollow example of society’s need to sanitise the distress caused by events beyond our control⁴⁶⁶ (p.33). If we were starting again, a more neutral term such as a discovery approach or a forward-focussed approach would be preferable. But we are where we are. One positive suggestion would be to focus more on working within the Personal Recovery Framework and avoid sometimes polarised discussions about recovery as a concept.

However, the level of emotion often contained in this criticism suggests that it is not really about inexactitude of meaning, but more concerned with the underlying shift in values. As Oyeode put it, ‘the involvement of governments in this endorsement of a peculiar departure in ordinary language demonstrates that we are here dealing with the politics of healthcare and not the clinical aspects’⁶⁰⁷. It does indeed. The real issue underpinning this objection may be a core disagreement with the whole recovery approach – an important, but different, concern.

People with mental illness lack capacity, so cannot take responsibility for their own lives

The embedded assumption that capacity is discontinuous, unidimensional and permanent is not true. It is true that a person with a mental illness may at particular times lack capacity to some degree in some areas of their life. In this, they are clearly similar to anyone else who has ever been drunk, excessively sleep-deprived, felt uncontrollable anger, or in any other way experienced a temporary loss of capacity. This understanding of capacity is much more useful, because it acknowledges that lack of capacity is possible, but assumes that the ability to express preferences and take some degree of personal responsibility is the norm rather than the exception. So the challenge is one of balancing the recognition that someone may have temporary decision-making incapacity whilst creating an orientation towards enhancing rather than diminishing an individual’s ability to take personal responsibility. Even during crisis it is possible to minimise the loss of autonomy (see [Chapter 21](#)).

My job is to act in the patient’s best interests, not on the basis of what they say they want

A focus on personal recovery is not consistent with this belief. History suggests that making decisions for people with mental illnesses has led to harm for many people (see [Chapter 7](#)). Also, such an approach is out of step with societal values: when people consult an expert, they expect to be given relevant information and then be the one who decides on action, either by stating their wishes or explicitly giving permission to the expert to decide. Why should it be any different for people with mental illness?

My job is to treat people

That is what many clinicians were trained for, and treatments are a major strength of mental health services. But we now recognise that an exclusive focus on treating illness is insufficient for some patients, and toxic for others (see [Chapter 1](#)). Focussing on promoting recovery involves placing more importance on well-being, on keeping the person in their life, and on the development of valued social roles and a positive identity (see [Chapter 9](#)). Clinical treatment skills are a vital contributor to this process for many people, but treatment is a means of meeting recovery goals, not an end in itself (see [Chapter 18](#)). The paradox is that working towards the individual’s goals will lead to greater engagement in treatment, because it is then linked to a personally valued goal rather than because someone

else thinks it is in the person's best interests. The job of a recovery-focussed clinician is to support recovery, not to provide treatment.

'You'd better wait until you're better before going back to work'

A key insight of a recovery approach is that it is unhelpful to put life on hold until the mental illness is successfully treated. Rather, it is better to put clinical effort and resources into helping the person to keep their life going, to retain existing social roles and to develop new roles. Work, as one of the primary means by which many of us define ourselves, is a vital early focus, and not something to consider at some point in the future.

How do I manage risk in a recovery-focussed service?

There is a political and professional reality that this is an expected function, so it is an important component of a recovery-focussed mental health service. Key strategies are distinguishing between harmful risks and positive risk-taking, having organisationally endorsed approaches to setting treatment goals to minimise harmful risks and recovery goals to maximise risk self-management, valuing the dignity of risk, and giving primacy as much as possible to recovery goals over treatment goals (Chapter 17). This involves reflective practice around how to minimise the clinical resources put into meeting treatment goals and maximise the clinical resources put into supporting recovery goals.

What is a recovery-focussed response to people who are a danger to themselves or others?

Key clinical strategies are: (i) skilled and collaborative assessment; (ii) promoting risk self-management by supporting the growth of personal responsibility; (iii) focus on the development of valued social roles, which buffer against acting on harmful impulses; (iv) use WRAP and early warning signs work to avert crises; (v) use advance directives to minimise loss of autonomy during crisis; and (vi) intervene with minimal compulsion where necessary (see Chapter 21).

What are the central values of recovery?

The core value is the primacy of personhood (see Chapter 15). As Bill Anthony put it, 'People with severe mental illnesses are people'⁴⁵³. This sounds prosaic, but is in fact transformational. It has implications for how clinicians relate to consumers (Chapter 13), seeing a person not an illness (Chapter 16), basic expectations of a good life for the person (Chapter 14), where responsibility for change lies (Chapter 18), needing the expertise of lived experience to do the clinical job (Chapter 12), and challenging stigmatising views held by clinicians and the public (Chapter 23).

Recovery will lead to a neglect of people with the most complex health and social needs

If the values of recovery are understood, there is no reason this should be so. Recovery is not about working mainly with people who are making progress and improving, or abandoning the most disabled. It is about using a different approach with exactly this most challenging group of people, to support them to lead the best life they can, *as they define it*. For some people, the gains will be very modest, and they will need long-term high levels of support. This, of course, should be available. Dependency is not a dirty word! The challenge, though, is to exhaust every avenue of support before reducing ambitions for the person.

Recovery is actively unhelpful for severely disabled people

The concern here is twofold. First, that setting up expectations of a better future will lead to hopes being dashed. However, we cannot judge who can recover, and therapeutic nihilism is self-fulfilling. Better surely to expect good things than to communicate impoverished expectations?

The second concern is that this will lead to people being abandoned¹⁵²: ‘Many individuals are so disabled with mental illness that they do not have the capacity to understand that they are ill. Giving such individuals the right to make decisions about their treatment is tantamount to abandonment’ (p. 1464). This argument is particularly consonant with a perspective that mental illness is *essentially* a biological disorder⁶⁰⁸. We argued in [Chapter 2](#) that this view of the person is unhelpful – mental illness is *essentially* a subjective experience, often of course expressed in a biological substrate. Similarly, recovery is not a thing you do once better, it is about winning small (and big) battles starting where you are. The challenge is supporting the person, whatever perceptions the observer has about their disability, to maximise what they can do, to work towards taking responsibility for their own lives, and to have hope for a better future. It is perhaps those people who are seen as most disabled, and written off as (literally) no-hopers, who have most to benefit from a recovery-focussed approach.

Diagnosis is a central protection for vulnerable people

This argument was first put forward by Anthony Clare²⁶⁹ in his seminal book *Psychiatry in dissent* as a response to the antipsychiatry movement:

What protects the dissident, the deviant, and the outsider from being labelled ‘mentally ill’ is not the psychiatrist who does not believe in psychiatric classifications. . . but rather the psychiatrist who acknowledges that people can suffer from serious mental disturbances, that the symptoms of these can be grouped and defined in such a way as to produce a reasonable degree of agreement to their validity and reliability, and that those people who do not show such symptoms cannot be classified as mentally ill, whatever society may say or do.

(p. 156)

One can look at this in two ways. On the one hand, it is true that diagnostic taxonomies provide, if not protection, then at least the ability to argue that what is going on is not psychiatry. We mentioned in [Chapter 7](#) the use of psychiatry for political purposes in the Soviet Union²⁷⁸ and China²⁷⁹. On the other hand, there has not been a visible outcry from clinicians about other developments, such as the political construction in England of diagnoses such as dangerous and severe personality disorder, whose ‘societal and legal convenience may appear substantially to exceed their clinical provenance’⁶⁰⁹ (p. 344). Other issues with diagnosis were explored in [Chapter 2](#).

The best balance point in promoting personal recovery is to view diagnosis as one highly developed and often useful tool, but only a means to an end, not an end in itself. The job of mental health services is not to diagnose and treat, but to support personal recovery. This may involve providing an explanatory model in which diagnosis features centrally. Or it may involve supporting the development of direct meaning in which diagnosis is peripheral. Or, most challengingly for current practice, recovery for some consumers may have nothing to do with (and be actively hindered by a clinical focus on) diagnosis.

People have a right to know their diagnosis

True, but misleading. If what is meant is simply that clinicians should share their understanding of what is going on with the consumer, then this is true as we emphasise in [Chapter 16](#). Information should not be withheld when the individual asks for a clinical view. It is also the case that sometimes (as when the diagnosis is particularly stigmatising, such as schizophrenia) there is an argument that this should be shared slowly over time to allow integration and adjustment, but the goal should be openness and clear communication. The role of professional expertise and clinical judgement in the relationship is central.

However, it is misleading if the implicit assumption is that the diagnosis represents the privileged insight held by the clinician into what is really going on for the person, i.e. the person has the illness and it is the clinician's duty to let them know that they have it. This reification of diagnosis was challenged in [Chapter 2](#), and it works against the tentativeness which is a central value for personal recovery. There is a world of difference between 'You have schizophrenia' and 'What you've described can be understood as being symptoms of schizophrenia'.

There aren't resources to offer treatments, so how can we be expected to do more tasks?

For over-worked, under-resourced clinicians this is a barrier to any change. Two suggestions are to spend differently and to 'code-share'. Spending the available resources to support recovery will be more effective than spending on the treatment of illness (See Case study 18). Code-sharing is the practice of an airline selling seats on a flight operated by another airline. Many must-do clinical activities can be done in a recovery-promoting way, to both feed the beast of professional or administrative requirements and to take advantage of the fact that the beast doesn't generally care what it is fed. So work differently, not more. Focus treatment planning towards recovery goals rather than treatment goals. Positively discriminate in favour of people with lived experience of mental illness in recruiting mental health staff. Harness the energy of consumers to run groups and develop community links. Train consumers to speak for the team to media. If placement reviews are the required mechanism to ensure taxpayers get value for money, then this has to be done – but by whom? Can some consumers in placements be supported to review the placement themselves? Can a consumer be trained in placement review as a means of developing job-related skills? If risk management plans are compulsory, then what stops it including a section on growth opportunities (i.e. risks needed for personal growth)?

We would do this if we weren't so over-run with trying to meet endless need with minimal resources

This realistic concern is important. It is unrealistic to expect hopeless and disempowered workers to promote recovery, or to expect clinicians to get to know someone if they have minimal interaction time and large amounts of paperwork, or to expect recovery-focussed services to be a way of saving money. A key function of leadership is to create an organisational context in which recovery-focussed work is possible, which will involve addressing these barriers to change.

What are the implications of recovery for the professions?

We don't know. Some potential positives are increased job satisfaction, less compulsory treatment ([Chapter 21](#)), seeing people moving on in their lives beyond what anyone thought possible ([Chapter 18](#)), and developing exciting new roles as promoters of well-being

(Chapter 14). There are potential negatives: professional role uncertainty (Chapter 13), leadership tensions (who should lead a clinical team?), values conflict where the professional identity emphasises nomothetic knowledge (Chapter 4) or deficit amelioration (Chapter 2), increased self-awareness about stigmatising beliefs (Chapter 12) and loss of status (e.g. in salary, or in relation to other specialities in the same profession).

Concerns held by consumers

We consider here some of the concerns which I have heard raised by consumers about the recovery approach.

Recovery is a medical term

It does have medical overtones, although recovery in the sense in which it is used here has emerged from the stories of people who have experienced mental illness, rather than from clinicians. This is an example of where partnership is needed – if the clinical community seeks to understand and communicate this understanding of recovery back to the service user/survivor community from which it emerged, it is very likely to be framed as a professional initiative. What is needed is a mature service user–professional partnership, in which the values and practices of recovery are communicated to a service user audience primarily by other service users.

Interestingly, in New Zealand, which probably has the longest history of trying to develop recovery-focussed mental health services, there is a growing recognition of the need for consumer training in recovery – supporting individual service users to engage with mental health services in ways which support their own recovery.

There isn't one route to recovery, or one recovery model

Absolutely. Therefore it is more useful to talk about recovery as an approach, a set of values, or overarching guiding principles. As Repper and Perkins point out⁴, this 'circumvents sterile arguments between competing intervention models (medication vs. therapy vs. employment vs. self-help vs. complementary therapy, etc.). All or none of these may contribute to the central overarching goal of growth and development'. This is why there is no mention in this book of *a* recovery model. Rather, a focus on personal recovery means incorporation of a set of values, and consequent working practices, into mental health services. That said, clinicians do think in terms of models. The Personal Recovery Framework presented in [Chapter 9](#) seeks to bridge the gap, by being sufficiently individual to highlight the unique and idiosyncratic nature of recovery, whilst sufficiently general to be of use across mental health services.

Recovery is a cover for service cuts

Recovery has been used as a justification for cuts to services. A cost-reducing element of a recovery-focussed mental health system is the dismantling of mental illness ghettos, such as day-care services and daytime activities exclusively for people with a mental illness. A cost-generating element is the creation of pathways to social inclusion, including accessing normal mainstream community resources and opportunities to exercise full citizenship rights. Similarly, reducing dependency may lead to more people moving on from services (saving money), but working in an individualised way with each person is more time-consuming (costing money). The financial implications of a shift in values and practice

towards personal recovery are unknown, but substantial cost savings are unlikely. Saving money by closing ghettoising services and increasing throughput without spending money on creating pathways into society and staff capacity to work alongside people as they struggle to re-engage in their lives should not be presented as a means of promoting recovery.

Taking away diagnostic labels will reduce access to services and benefits

Diagnosis is the means of access to many important forms of support, so in the short term diagnostic terms will remain important as gateways to health and social benefits and entitlements. A focus on personal recovery does not mean abandoning a diagnostic frame of reference. Rather, it means moving from diagnosis as a revealed truth to diagnosis as a working hypothesis to make sense of the individual's experience. Genuinely allowing individuals to determine their own meaning will involve open discussion about the merits of accepting or using a diagnostic label. For some people, the use of a diagnosis will fit their experiences and provide a helpful way forward. For others, they may not fully or at all understand their experiences within a diagnostic framework, but will accept the use of the diagnosis in order to access societal benefits. For others, they will decide that the use of a diagnostic label is personally unacceptable, even if this means not being able to access social benefits. The central principle is informed choice.

Recovery will be neutralised by professionals

There is a danger that the term becomes appropriated by professionals as a means of retaining the *status quo* and ensuring business as usual. The absence of any accreditation process for labelling a service as recovery-based creates the very real possibility that recovery teams will be established whose philosophy is based on clinical recovery, with primacy given to professional concerns about symptoms, risk, etc. Similarly, consumers often voice concern about the individualised nature of recovery becoming 'the recovery model' by the time it reaches professional level of discourse, suggesting a production-line mentality in which recovery is the next thing that professionals do to consumers.

This issue has been addressed in three ways. First, the difference between personal and clinical recovery was identified in [Chapter 3](#). The aim of this book is to translate the consumer-developed idea of personal recovery into clinical practice, not to legitimise the professionally developed idea of clinical recovery. Second, the values and working practices needed in a mental health service focussed on personal recovery have been outlined in [Chapters 15 to 21](#), and they are certainly not business-as-usual. Third, quality indicators for a recovery-focussed service have been proposed in [Chapter 22](#), which make the embedded values transparent and amenable to debate.

Recovery is a consumer-developed concept being appropriated by professionals, when it's nothing to do with them

Underpinning this concern may be a view that the incorporation of the user-developed concept of recovery into mental health services necessarily involves a loss of its radical and oppositional edge, so there can be no real shifts in power and it will simply involve processing patients in a slightly different way: using modified language but with the same ultimate aim of controlling the individual. This criticism is difficult to address without agreeing with assumptions implicit in the concern. It is a central assumption in this book that mental health services have much to offer many, though not all, people with mental illness, and that whilst the mental health system has some damaging emergent properties, the vast majority of the individuals working in the system are altruistic, compassionate and

skilled people. Supporting the consumer-developed idea of recovery will involve core shifts in the values and practices of mental health services. Persuading oppositional consumer activists – who view collaboration with services as ‘supping with the devil’⁶¹⁰ – to move from a position of outsider to a position of partnership will be an indicator of the success of mental health services in embracing and operationalising personal recovery values.

All this talk about recovery ignores the human suffering caused by mental illness

A focus on personal recovery does not mean ignoring the all-too-real human suffering. It also does not involve being relentlessly up-beat in the face of this suffering. Acknowledging when life is hard is an authentic and helpful response for both the person with a mental illness and the professionals and non-professionals in their life. However, the development and consolidation of identity, the finding of hope, the creation of meaning and the grasping of personal responsibility all create ways forward from this suffering.

The recovery approach imposes a set of values on the individual

This concern can be held at two levels. First, the recovery literature is permeated by implicit notions of how people should be. The North American recovery literature ‘projects traditional American values onto disabled people, such as rugged individualism, competition, personal achievement and self-sufficiency’, and does not appreciate that for some people, ‘independent living amounts to the loneliness of four walls in some rooming house’¹¹⁹. An emerging counterpoint is the New Zealand experience, which is influenced by non-American cultural views. Similarly, in this book the concept of identity (described in [Chapter 9](#)) has been deliberately positioned as neutral towards whether primacy should be given to the individual or the person-in-context.

A second level of this concern is as a tautology – any approach to working with other people contains implicit assumptions about values. Given that reality, it is helpful to make the values transparent, which at least makes them amenable to debate. This involves more explicit recognition of the values base held by practitioners, and its potential impact on clinical practice. As Bill Fulford put it, ‘If . . . a psychiatrist cannot distance herself from the ideas about beneficial treatment endorsed by her profession, it is unlikely that they will appreciate the reasons behind their patients’ preferences and concerns or will altogether fail to elicit these’⁶¹¹ (pp. 706–707). Making values clear also allows services to be held accountable for living by them. For example, the closure of day centres or reduction in peer support services or imposing individual over communal living under the justification of increasing social inclusion can only be effectively challenged by holding the mental health system to account for the extent to which its services match its stated values.

I don’t understand my experiences in a medical framework

A great advance offered by a recovery approach is that this is fine – the meaning of choice is the choice of meaning. A recovery-focussed mental health professional doesn’t care what label someone puts on their experiences, or whether they accept they are ill. To an extent they even don’t care about compliance with medication or treatment. Their starting point is what the person wants in their life. Their goal is to work collaboratively towards the consumer’s goals, bringing their professional training as a resource to add to the person’s expertise about their own experiences, values and goals. Because this means working differently to how many professionals were trained, consumers can help this process by communicating their goals as clearly as possible.

Taking responsibility is hard

Yes, it is. And so too is continuing to carry responsibility for one's life. Recovery is about values, and one value is that taking responsibility is an important underpinning for a good life. Clearly, some people at some points in their life cannot take full responsibility for themselves. One reason, amongst many, is mental illness. A recovery-focussed mental health service takes as little responsibility as possible away from the person, and actively supports the person to take back partial or full responsibility for their own life as soon as possible. This process can take time, as the person slowly builds confidence and skills at running their own life.

I may not meet expectations – recovery sets me up to fail

Failure is possible. Real success is not possible without the chance of failure, so people in recovery from mental illness can (and will) experience setbacks. Just like everyone else. The only way to avoid the chance of failing is to disengage from trying anything. The central recovery value is that engaging in life is better than trying to survive life. This is a value, not an objective truth. It is also not the only view – not everyone agrees with Tennyson that 'Tis better to have loved and lost than never to have loved at all'⁶¹². What is proposed here is that holding and communicating expectations of an engaged, meaningful and productive life is a *better* value for mental health services. The job of mental health professionals is then to be actively supporting the individual, both by helping the person to develop the skills and confidence to take on challenges, and where helpful to be a safety net for the person if things don't work out as planned.

I have nothing to recover to

The language of recovery may sound hollow to someone experiencing strong incentives to retain what status they have as a person with a mental illness, rather than trying to operate in a discriminating and suspicious society. So it is understandable that, initially at least, life as a patient may seem more attractive. But this simply points to the central challenge, which is finding the hope that meaning and purpose are possible, that an identity which is not defined by the mental illness can be developed, and that a valued life is attainable. This involves a move from an entitlement to an empowerment mind-set, which is difficult. Increasing the visibility of role models is a central contribution of mental health services to this process. Alongside this, part of the job of mental health professionals is improving social inclusion – working with communities to widen opportunities.

In this concluding chapter, concrete actions are proposed for mental health services which want to develop a recovery focus. Moving towards this focus will involve doing things differently, which is likely to include seven key actions.

Action one: lead the process

Leadership differs from management. Managers solve problems to make the organisation work more effectively or efficiently, and their basic orientation is towards control and administration. Leaders build the organisation's future, and their basic orientation is towards inspiring, influencing and guiding. Evolving towards a recovery focus starts, but does not end, with leadership. The first action is then to employ and legitimise leaders rather than managers in organisational positions of influence.

Bill Anthony identifies eight leadership principles⁶¹³, shown in Box 26.1.

Leaders understand that systems, like people, don't change easily. There is a need to introduce a level of survival anxiety – a sense that things cannot continue as they are. It often takes a jolt to the system to create change. For example, the Georgia Certified Peer Specialist Project began when the state government threatened to ask for a repayment of funds from the statutory mental health service after lobbying by local consumers about unsatisfactory outcomes and insufficient move-on⁶¹⁴. It is now established with both state and federal funding³⁶⁸. Leaders recognise the stages of transforming systems⁶¹⁵:

1. Establishing a sense of urgency
2. Forming a powerful guiding coalition
3. Creating a vision
4. Communicating the vision
5. Empowering others to act on the vision
6. Planning for and creating short-term wins
7. Consolidating improvements and producing still more change
8. Institutionalising new approaches

Key leadership strategies follow from this analysis.

Raise awareness

Measure and publicise empowerment levels among consumers. Support people to talk about their own recovery stories. Highlight anti-recovery practice. Audit treatment and care plans for the extent to which they promote self-determination and autonomy. Create token consumer roles on influential boards. Import charismatic recovery champions, either permanently into the workforce or temporarily as invited speakers at local events. Visit demonstration sites. Link in with existing networks (e.g. Coalition of Psychiatrists in Recovery – www.wpic.pitt.edu/AACP/CPR). Learn from others (e.g. www.calmend.org).

Box 26.1 Leadership principles

- Principle 1: Leaders communicate a shared vision
- Principle 2: Leaders centralise by mission and decentralise by operations
- Principle 3: Leaders create an organisational culture that identifies and tries to live by key values
- Principle 4: Leaders create an organisational structure and culture that empowers their employees and themselves
- Principle 5: Leaders ensure that staff are trained in a human technology that can translate vision into reality
- Principle 6: Leaders relate constructively to employees
- Principle 7: Leaders access and use information to make change a constant ingredient of their organisation
- Principle 8: Leaders build their organisation around exemplary performers

Create survival anxiety

Support existing consumer coalitions – their voice is often much stronger than clinicians’ in calling for change. Support individual consumers wanting to complain. Develop advocacy services. Pilot pro-recovery ways of working. Locally publicise pro-recovery national policy. Encourage consumers to tell their stories in local and national media. Stock-take and publicise the level of valued social roles and rights (work, intimate relationships, housing, income). Increase disclosure in the workforce by including personal experience of mental illness as a desirable criterion in all job descriptions.

Develop new coalitions

Seek out local and national allies. Form local networks. Actively promote – literally if possible – recovery champions. Get to know influential opinion-formers and encourage pro-recovery values in them. Develop personal support networks to remain hopeful. Create a ground-swell about recovery by local learning sets, recovery meetings and team or programme-level commitments. Align with influential people who are highly negative in their views about recovery around a shared goal of making the lives of consumers better and ask for their help, rather than directly try to change the person into a recovery adherent. Remember that ‘when you pit a bad system against a good performer, the system always wins’⁶¹⁶.

Have a plan

Act strategically and use the limited resource of your time and energy as productively as possible. Separate means and ends. Drop the term recovery if it provokes a knee-jerk negative response – find a more acceptable local term. Analyse organisational readiness to change^{454;617}. Develop staff knowledge through teaching sessions (many short sessions, not one long session), policy, induction procedures, day-to-day discourse, educational materials, research presentations, conference attendance. Shape values through visits to exemplar sites, exposure to recovery narratives, consumer employees, supervision practices, management messages about the primary purpose of the organisation, workshops on values, bringing recovery heroes into the system as invited speakers or as employees. Increase skills through targeted skills workshops, supervised practice, leadership from opinion-formers, telling and supporting staff to change behaviour, new clinical processes. Embed change through a clear and visible mission, reviewing policy, amending record-keeping, using programme development consultancy expertise, asking all parts of the system (e.g. IT, human resources) to

prepare recovery business plans – what they will do to support a recovery focus. Work around resistance rather than through it. Have goals about organisational transformation and celebrate success when they're met. Review the plan – as Winston Churchill put it, 'However beautiful the strategy, you should occasionally look at the results'. Learn from others^{91;613;618}.

Action two: articulate and use values

The second action is to make the organisational values explicit, and to collate and use evidence of consistency between these values and working practices. This involves difficult discussions about core values and identity. For example, some commentators propose that⁶¹⁹: 'the medical/illness-based paradigm from which our mental health system has historically operated is perhaps the single-most overarching barrier impeding both consensus and implementation of person-centered planning' (p. 12). One component is the development of new clinical sayings. The Collaborative Recovery Model (CRM)⁶²⁰, described in Case Studies 10 and 21, uses these:

1. Recovery is responsibility
2. Hope helps
3. There is evidence for alliance
4. Roll with resistance
5. Develop discrepancy
6. Avoid argumentation
7. Motivation is malleable
8. Champion capacity; disable deficit
9. Needs are negotiable
10. Goals should be meaningful, not just manageable
11. Review, Design, Assign [for homework tasks]

How is this translated into practice? Our next case study illustrates some of the benefits and challenges⁶²¹.

Case study 21: implementing the Collaborative Recovery Model

SNAP Gippsland Inc. began as a non-governmental housing initiative in 1992, and diversified into a focus on day programmes in 1996. It serves a rural population in south-east Victoria, and provides community-based support to people with mental illness. In 2003 the organisational commitment to recovery led to employment of a worker who had completed a one-year supervised training programme in the Collaborative Recovery Model (CRM). A condition of employment was that CRM be implemented in undiluted form. During the first three months employment, the CRM trainer led a top-to-bottom audit of the organisation's recovery focus. Following this review, a number of organisational change strategies have been implemented:

- Training staff in CRM, and then expecting the protocol to be used with at least one client, followed by more over time
- Developing supervision arrangements to promote reflective practice
- Developing personal mentorship arrangements
- The CRM trainer audits all paper-work, to maximise model fidelity
- Maintaining links with relevant academic centres, through monthly teleconferences and biannual visits. This enhances local credibility, and provides access to emerging practice developments

Case study 21: (cont.)

- Hosting a recovery-themed local conference with both internal and external speakers, to celebrate success, disseminate local stories of recovery, and promote a system-level identity as a recovery centre of excellence.

A central implementation step has been developing shared ownership: 'The whole organisation, from service-users to the Board of Management, must own and embrace the model in order to change the mindset and practice of the organisation as a whole' (p. 43). *For consumers, a developmental approach is needed*: 'Not all of my clients are happy to change to the CRM because they find it a bit scary. I'm working these clients up to it and slowly teaching them about the new program' (p. 48).

The reason these ideas have taken hold is because of their transformative potential. For example, Danielle is a woman with a history of multiple admissions, self-harm attempts and diagnoses (schizophrenia, depression, substance abuse) who was able to identify and implement a recovery goal of swimming with whales in Tonga. Or Ron, who reports 'One of the things about SNAP is that the people there can help you, but you have to do the work. I'm proud because I have accomplished things. I'm more open. The petals are open' (p. 59).

The service is now working with the idea of exit interviews with clients, to seek to understand their experience of using the service. This requires consideration of power issues (the person may come back, so may not feel they can be honest), who should do the interview (e.g. a consumer-advocate) and what to ask.

Key challenges have been:

- High turnover of SNAP workers, due to staff being unwilling or unable to move with the organisation: 'taking ownership of the recovery model represents a change in identity for the organisation' (p. 56)
- Employment of consumer-employees, who have not been able to separate their own recovery journey from that of the client they're talking with, leading to advice-giving on the basis of what worked for them. This has been exacerbated by a rhetoric about the consumer having the most expertise about recovery, which has now been refined to the consumer having the most expertise about their own recovery journey
- Difficulties in embedding ownership, shown by a high burden resting on the chief executive officer and the CRM trainer with consequent concerns about sustainability.

Further information: www.snap.org.au

Action three: maximise pro-recovery orientation among workers

Consumer narratives emphasise the importance of personal characteristics of the worker, in addition to technical competency. Desirable qualities include being kind, tenacious, tolerant, positive, warm, compassionate, optimistic and hopeful. The importance of being able to relate to people with mental illness as a person rather than an illness is central. Yet mental health services have traditionally emphasised technical competency, professional group and accreditations, rather than personal qualities. This has practical implications: core professional training is one barrier to a focus on personal recovery⁶²²:

An analysis of the training standards and curricula for psychiatrists, comprehensive nurses, diploma level social workers and mental health support workers showed that there are some gaps in the recognition of recovery competencies . . . There was little or no reference in most of these documents to:

- a recovery approach
- the different understandings of mental health and mental illness
- supporting the personal resourcefulness of service users

(p. 1)

This is beginning to change, with the development of recovery competencies. In New Zealand there is a recognition of the scale of the task²⁹²: 'The recovery-based competencies . . . signal a fundamental change to all aspects of the education of mental health workers. They require that some new material be taught. But they also require that some existing material be taught differently' (p. 2). The ten New Zealand recovery competencies⁶²² are shown in [Box 26.2](#).

As another example, a review of the capabilities needed by a modern mental health workforce in England identified gaps in professional training in relation to: user and carer involvement; mental health promotion; values and evidence-based practice; working with families; multidisciplinary working; and working with diversity. This led to the development of ten Essential Shared Capabilities as a foundation for all workers in the mental health system⁶²³, shown in [Box 26.3](#).

What both these approaches have in common is that they relate to *how* staff work with patients. The third action is therefore to increase the pro-recovery orientation of workers in the system, through both recruitment strategies and workforce development.

How can people with pro-recovery views be identified during recruitment? Being explicit about organisational values in the information about the post allows potential applicants to self-select. Interview questions such as 'Why do you suppose people with psychiatric disabilities want to work?' give a chance for applicants to demonstrate their values. Involving consumers and carers in the recruitment process gives some information about how interviewees relate to people they will work with. The Boston University Center for Psychiatric Rehabilitation requires basic knowledge, attitudes and skills in relation to recovery to be shown during selection⁴⁵⁴:

Box 26.2 New Zealand recovery competencies

A competent mental health worker . . .

1. understands recovery principles and experiences in the Aotearoa/NZ and international contexts
2. recognises and supports the personal resourcefulness of people with mental illness
3. understands and accommodates the diverse views on mental illness, treatments, services and recovery
4. has the self-awareness and skills to communicate respectfully and develop good relationships with service users
5. understands and actively protects service users' rights
6. understands discrimination and social exclusion, its impact on service users and how to reduce it
7. acknowledges the different cultures of Aotearoa/NZ and knows how to provide a service in partnership with them
8. has comprehensive knowledge of community services and resources and actively supports service users to use them
9. has knowledge of the service user movement and is able to support their participation in services
10. has knowledge of family/Whānau perspectives and is able to support their participation in services.

Box 26.3 The ten Essential Shared Capabilities in England

1. Working in partnership
2. Respecting diversity
3. Practising ethically
4. Challenging inequality
5. Promoting recovery
6. Identifying people's needs and strengths
7. Providing service-user-centred care
8. Making a difference
9. Promoting safety and positive risk-taking
10. Personal development and learning

Basic knowledge includes knowing the current research with respect to recovery and recovery outcomes as well as, for example, research related to the role of prejudice and discrimination as obstacles to recovery. Basic attitudes include the extent to which the four key values [*person orientation, person involvement, self-determination, growth potential*] are incorporated into a candidate's way of thinking about individuals with disabilities or psychiatric histories . . . Basic skills include skills such as the skill of engaging an individual in a partnership, inspiring hopefulness, connecting with that individual in a personal way, as well as supporting and facilitating the individual's recovery journey.

(pp. 153–154)

For the existing workforce, stage-based training is needed. For workers in the precontemplative phase, approaches include learning about recovery (using websites with recovery-focussed resources – see Appendix), reading the accounts of recovered consumers^{55;106–108;118}, understanding how recovery happens in stages^{123;137;318}, exposure to people in recovery, and training on national policy. For those in the contemplative phase, staff development approaches include identifying personal values and practices³⁰⁹, developing communication skills through reading information written for consumers about recovery^{28;296;624;625} and visiting demonstration sites.

Like several others, this action is not possible without support to legitimise doing things differently. The more powerful the support is, the better. Radical transformation at the national level is occurring in some countries, notably New Zealand and Italy. In New Zealand, the shift towards non-governmental organisation involvement in *providing* services emerged from a system-level crisis, and has required radical shifts in core assumptions.

In Italy, system transformation has involved a focus on laws rather than policies. The advantage of a legal framework is that laws are subject to judicial oversight, and in contrast to policies they cannot be easily sabotaged by unenthusiastic clinicians or managers, or by resource arguments. See www.triestesalutementale.it for more information.

Case study 22: implementing pro-recovery policy

After 67 consecutive inquiries, it became clear that the mental health system in New Zealand was unable to improve acute care services through internal change. In 1996, Judge Ken Mason produced a report into mental health services⁶⁰². Unlike the previous inquiries, the Mason Report led to innovative developments. It made a small number of recommendations:

Case study 22: (cont.)**1. A national anti-stigma campaign**

This was described earlier in Case study 20.

2. A coordinating Mental Health Commission

The Commission has overseen the strategic development of mental health services, and its directors come from both mental health professional and consumer backgrounds. It has published many practical resources, including the recovery competencies for mental health workers²⁹², a systematic review of the evidence about consumer-led services²⁹³ and recovery-focussed research on consumer narratives¹⁰⁷, media reporting²⁹⁴ and in-patient²⁹⁵, home treatment¹²⁴, forensic¹²⁶ and early psychosis¹²⁵ services. Two publications to highlight are a consumer-written guide for service users to get the most from mental health services²⁹⁶, and a celebration of recovery-focussed mental health workers²⁹⁷. Both contribute to the mature and genuinely collaborative relationship needed for mental health services to promote recovery. All are available at www.mhc.govt.nz.

3. A funding stream which came to be known as Blueprint funding

The Blueprint was published in 1998²⁹¹, and stated:

Recovery is a journey as much as a destination. It is different for everyone . . . Recovery is happening when people can live well in the presence or absence of their mental illness and the many losses that come in its wake, such as isolation, poverty, unemployment, and discrimination . . . Historically, mental health services have failed to use a recovery approach. Recovery could never take place in an environment where people were isolated from their communities, where power was used to coerce people and deny them choices, and where people with mental illness were expected to never get better. Some people have experienced recovery without using mental health services. Others have experienced recovery in spite of them. But most will do much better if services are designed and delivered to facilitate their recovery.

(pp. 1–2)

This statement involves a commitment to a recovery-focussed future (which is now common in international policy) and a recognition of past failings (which is unique to New Zealand). This latter aspect may be the reason why the policy commitment to recovery has become deeply embedded in practice. An important engine of innovation has been Blueprint funding – the partial redistribution of public funds for acute care outside the statutory sector. For example, this led to the development of peer-led and peer support services, including the in-patient unit described in Case study 15. This creates flexibility in services, and means there's more than one model – and hence more than one real choice.

Looking back on the impact of his report, Mason commented that 'A huge advantage of our inquiry was that we weren't required to look at issues of guilt, as so many inquiries are. What we had to determine was whether there were deficiencies within the system . . . and how could they best be resolved'⁹¹ (p. 5).

There are ongoing challenges. It has been difficult to make the development of recovery a whole-system approach. For example, a lot of resourcing has been focussed on in-patient services, which are arguably not the best start point because the primary goal is often safety, and the expectations of disempowering coercion are highest. Other system transformation challenges have been:

1. Embedded attitudes amongst professionals
2. The change in the power relationships experienced by both clinicians and the families of service users
3. The development of better exit strategies – how to move people on from the mental health system

Case study 22: (cont.)

4. The shortage of access to adequate housing and employment
5. Keeping people's lives afloat during admission. On admission people often aren't asked whether they have children, other dependants or pets, and they don't volunteer this information for fear they'll be taken away. The challenge is keeping employers in the loop, and more generally keeping life on the go whilst the person is ill.

The next phase in the evolution of services will be to link the recovery concept with the Māori concept of Whānau Ora – wider population-level understandings, such as resilience. Although older consumer activists prefer the term recovery (as it has produced a partial power shift), younger people prefer the less stigmatising term resilience – everyone needs resilience, but only ill people need to recover. This also links with the culturally embedded construct of resilience, which is needed by both the individual and the group to survive. It is therefore applicable to the whole population, and a necessary and normal component of individual and cultural well-being.

Further information: www.mhc.govt.nz

Action four: develop specific pro-recovery skills in the workforce

The next action is to develop three specific skills. The first is to train staff to assess capabilities as well as disabilities, and support the use of this skill through ongoing training and supervision. This skill is a necessary counterbalance to the deficit bias we discussed in [Chapter 2](#). How is this done? In Case study 13 we described a service based on the Strengths Model⁷². We now describe how the service change was made.

Case study 23: implementing the Strengths Model

Since 2004, workers in the St Vincent's Hospital system had been grappling to define the model for adult rehabilitation and continuing care services. Several models were considered in relation to:

1. evidence base
2. fit with existing service structures, language and practical constraints
3. existence of experienced clinicians who had implemented the model and were willing to share their experiences
4. being person-centred, based on consumer goals, with consumer-held records
5. fitting with local values of the hospital: Compassion, Justice, Human Dignity, Excellence and Unity.

Existing expertise in the Strengths Model⁷² was identified in Timaru Mental Health Services in New Zealand, which has been implementing the model since 2001. Staff from Timaru shared training materials freely, and were happy to discuss its implementation via videoconference. The decision was made in 2005 to adopt the Strengths Model at St Vincent's.

Implementation began with a visit by a multidisciplinary group of clinicians and managers from St Vincent's to Timaru. The programme comprised a five-day training workshop (as given to local Timaru staff), implementation planning and train-the-trainers work. The advantages of going to the expert service were that each stakeholder had more chance to address their own questions.

Managers wanted to know whether the service was sufficiently similar for comparison to be meaningful, whether it could be implemented locally, whether the model would build

Case study 23: (cont.)

on what was already in place rather than devaluing existing skills and whether the investment of time and effort was worthwhile. Managers saw the inpatient unit, met consumers, followed the use of documentation and talked with the local trainers and senior clinicians.

Clinicians were struck by the positive engagement approaches which were possible even with consumers who rejected illness labels or the need for treatment, the emphasis on learning and changing for both consumers and staff, the recognition of the self-fulfilling nature of a focus on problem and deficit, and the expectation that interventions are not planned or implemented without the approval of the consumer, except in the specific context of the Mental Health Act. The emphasis on the community as a supporter of recovery, rather than an obstacle to recovery, was congruent with assertive outreach approaches. The relationship between the clinician and the consumer correlated positively with good outcomes.

Following this visit, a series of two-day and shorter training courses have been run at St Vincent's. Training initially involved a local St Vincent's trainer and visiting Timaru trainers, using Timaru-developed training programmes. A training team has now incorporated local examples from both staff and consumers into the programmes, leading to greater local ownership and visibility of the model. Training is now provided exclusively by St Vincent's staff, with consultation support from Timaru.

The ongoing mentoring relationship has been experienced positively by Timaru staff, who identify the following benefits:

- affirmation of the Timaru service as being valued by others
- reassurance that local issues were similar to those faced by St Vincent's
- recognising that training in itself is insufficient, and having to make concrete the key elements needed for successful transition to the new model: developing a motivated group of key people, securing management buy-in, revising policy, conducting regular audits
- positive reinforcement of giving an open and welcoming response to enquiries from external services
- enhanced credibility with the local District Health Board

Overall this approach to system transformation has been positively valued by both sides. A term used is that the services are 'travelling together', indicating both value being placed on the current arrangements and a learning and development orientation towards the future.

Further information: Bridget Hamilton (Bridget.hamilton@svmh.org.au)

The second specific skill is identifying and planning action towards recovery goals. This involves clinical processes and working practices which orient mental health services more towards recovery goals, and views treatment goals as necessary but not the primary purpose of the organisation. A range of approaches were identified in [Chapter 17](#). Audit strategies can include the proportion of care plans which are focussed on recovery rather than treatment goals, the proportion which harness approach rather than avoidance motivation, and the extent to which attention (e.g. in clinical meetings) and resources (e.g. money, workforce skills) are focussed on recovery goals rather than on treatment goals.

The third specific staff skill is recognising the central importance of developing personal meaning. This involves links with mutual self-help groups, training for staff in the distinction between supporting meaning and promoting insight, and using written and verbal communication which validates the individual's perspective.

Action five: make role models visible

The fifth action involves services working in ways which make people in recovery more visible, to both consumers and staff. Potential initiatives include training in telling one's story (Case study 3), running events celebrating success (Case study 12), developing a consumer speakers' bureau and providing consumer-led staff training.

The development of peer support specialist roles in teams and employment of people in recovery from mental illness throughout the system is crucial. However, it is unlikely to be sustainable before the earlier actions. This involves ring-fencing dedicated posts for people with their own experience of mental illness throughout the system, and ensuring there is access to initial training and ongoing support for people in this role. The transformative potential of this single action is high, as shown in our next case study.

Case study 24: Recovery Innovations

META Services is a mental health service based in Phoenix, Arizona. In 1999 the organisation's chief executive, Gene Johnson, attended a national workshop in which service recipients talked about feeling continually discounted, disempowered and disrespected⁶⁰⁴. The discomfort created by this experience kick-started a process of organisational transformation, from being a traditional service provider to one where 139 (54%) of its 256 staff are peers. Peer-operated services now account for \$4m of its \$12m annual revenue⁶¹⁴. This transformation was done in stages⁶³⁰:

1. Revising the mission statement: 'Our mission is to create opportunities and environments that empower people to recover, to succeed in accomplishing their goals, and to reconnect to themselves, others, and meaning and purpose in life'.
2. Recruiting people with lived experience of mental illness ('peers') to the management team and into full-time (36%) and part-time (72%) posts at all levels in the organisation. These new peer recruits were carriers of a recovery culture into the organisation.
3. Achieving early wins, such as the elimination over a two-year period of seclusion and restraint from services.
4. Moving from a therapeutic to an educational model. This was central because 'we wanted our Centre to be about reinforcing and developing people's strengths, rather than adding to the attention placed on what was "wrong" with them'⁶³¹. Most training is prepared and delivered by peer specialists, such as WRAP⁶³² and many college credited and non-credited courses, tailored to contain a recovery focus. In 2006/07, 5660 people received 98 900 hours of education in 6730 classes.
5. A key innovation has been the Peer Employment Training Program, which is a 20-module, 80-hour training course to prepare people to work as peer support specialists. Entry requirements are lived experience, having a high school diploma, having completed a WRAP and wanting to attend and find a job. The course covers both general work skills and the role of the peer support worker (e.g. telling your personal story, being with people in challenging situations). Post-training options include an 80-hour internship, support from a job placement service, and 90-day employment follow-up services. In-class transformation is common: over 95% of participants graduate, and 89% of peer support specialists were working at one-year follow-up⁶³¹. The peer training is accredited, earning college credits which allow peers to work towards an associate arts degree. Ongoing support and supervision is provided for peer specialists, to avoid washout of their unique contribution. By June 2008, 796 peer specialists had been trained, of whom 76% have obtained employment. The training model is being adopted in other States and internationally (e.g. Scotland (see Case study 4), New Zealand).

Case study 24: (cont.)

6. Growing flexibly and opportunistically, by retaining the recovery values whilst responding to market need. For example, partnering with a local college to offer a wider range of educational options, developing a wellness centre, and creating innovative alternatives for people in crisis (see Case study 14).
7. Evaluation is central, since money identified as being saved on admission rates (reduced by 56%⁶³¹) has been used to develop new peer support worker roles, including: recovery educators and coaches in case management teams; crisis specialists in the Living Room; peer advocates in in-patient services; and peer recovery teams as an alternative to case management teams.

The driving force within the organisation has been placing value on lived experience. Since most of the workforce now have experience of mental illness in their lives or those close to them, the 'them-us' distinction is broken down; as one worker noted, 'it [mental illness] is all around us'. The 'them-us' distinction is further reduced by requiring peer and non-peer staff to go through recovery training together, which culminates in a 'telling your story' day in which participants describe a personal recovery experience. Sometimes this creates discomfort, when the organisation is confronted with its own professional biases and stigmatising beliefs and practices. The process of organisational 'recovery' has involved increasing the extent to which workers experience the five recovery pathways (choice, hope, empowerment, spirituality and recovery environment). The processes of organisational recovery parallel personal recovery in several ways: shifting from an entitlement to an empowerment culture; focus groups to understand the needs of staff rather than a sole focus on organisational imperatives; leadership training to enhance self-direction and self-management skills; supporting managers to 'get out of the way' of the worker's desire to do a good job, e.g. through the use of coaching (recoveryopportunity.com) rather than a prescriptive management style. Gene Johnson characterises the resulting changes as 'a profound, deep, intense, and penetrating alteration in the status quo'.

Further information: www.recoveryinnovations.org

Action six: evaluate success in relation to social roles and goal attainment

This action involves orienting the service towards supporting the attainment of valued social roles and personally valued goals by the individual. Once this orientation is in place, pro-recovery behaviours are increased by using these outcomes as key performance indicators by which organisational and individual worker performance is appraised. Our next case study describes one approach to identifying and evaluating recovery standards.

Case study 25: Recovery Devon

The county of Devon in England has a population of 850 000. Following a conference in 2003 with Mary-Ellen Copeland as an invited speaker, a recovery-focussed partnership of service users, carers and staff has developed, initially intentionally outside, but with informal support from, statutory sector services. Partnership activities included providing WRAP training³⁵¹ to over 300 staff and service users, establishing a quarterly newsletter and web-site (www.recoverydevon.co.uk), and developing intentional peer support training³⁶⁰. In 2006 a second conference was held, consolidating a 'recovery way of working' – again with inspirational invited speakers (Frank Bristol, David Gonzales, Shery Mead), a quota of an equal split of service user/carers and professionals, and name badges with first names only.

Case study 25: (cont.)

Since 2006 the Devon and Torbay local implementation team has provided the focus for a broad mental health and well-being network (growing out of this partnership), comprising commissioners and providers of mental health services from the statutory, voluntary and independent sectors. There is less need to refer to 'service users, carers and professionals' because (for some network members) this has become the meaning of these units – the them-us distinction has in places disappeared.

The voluntary and independent sectors have been an engine of innovation. For example, the Community Care Trust (www.community-care-trust.co.uk) is an independent provider operating in-patient and community-based services which focus on supporting recovery by:

- Inviting consumers to stay at the service when well, to get to know them and hence be holders of hope for them when in crisis
- Inviting consumers to bring a guest for a night or two when coming to the service in crisis, to make the admission experience safer
- Focussing on the development in its workforce of important qualities (e.g. authenticity, integrity, presence) in addition to skills
- Using coaching skills as the preferred method of interaction
- Signing up to holding others to account and being held to account in all matters, e.g. requiring all staff to complete WRAP, using a recovery approach to sickness self-management and disciplinary procedures
- Living the value of 'there is no other', so anyone using the service simultaneously becomes a resource for the service.

Informed by these innovations in other network members, the statutory mental health provider (www.devonpartnership.nhs.uk) has also identified an aim of 'putting recovery at the heart of everything we do'. Their service is being re-structured, with the design of each function being set by a professional expert group and endorsed by a clinical cabinet of senior clinicians, with accountability to a programme board. Change is being supported through the use of team coaches – 20 people are employed to work across 57 teams, supporting the teams to work better (e.g. through amplifying negotiation and conflict-resolution skills, supporting good leadership, encouraging reflective practice). Leadership buy-in has been increased by all the Trust executives attending WRAP training. Using these in-system approaches has maximised ownership of the change process.

Ten core standards for all commissioned mental health and social care services in Devon and Torbay have been agreed:

1. The recovery approach – all staff have relevant knowledge and skills
2. Recovery outcome evaluation – all services have a regular cycle of measuring recovery outcomes
3. Coherent and effective service configuration – services are constructed on recovery principles and delivered by teams that are managed and led so as to be coherent and effective contributors
4. Network partnership relationships – relationships are characterised by good communication, clarity, consistency and respect
5. Staff and service performance – all practitioners, teams and services are subject to regular performance review
6. The experience of networks – there is excellent 'customer care', receptive to personal preferences and diverse needs
7. Satisfaction – from those who use the services, their families and providers of related services. The general public have confidence in the services provided to their communities

Case study 25: (cont.)

8. Social inclusion – all services demonstrate practices which are supportive of people living ordinary lives in ordinary settings, especially in relation to accommodation, occupation, education, personal relationships, money and participation in community life
9. Building mental well-being – all service users and providers are supported to maintain well-being and build resilience
10. Challenging stigma and discrimination – all services are able to engage and effectively respond to issues of prejudice, stigma and discrimination.

The long-term aim is to 'design in' recovery into services by commissioning on the basis of these standards. Approaches to measuring success for each criterion (e.g. using DREEM⁶³³) are being investigated in 16 pilot sites.

Further information: www.recoverydevon.co.uk

Action seven: amplify the power of consumers

This final action involves ceding power, and occurs at the end rather than the beginning of organisational transformation. People with their own experience of mental illness are an under-used resource for organisational and societal change. Supporting consumer activism to challenge anti-recovery assumptions and obstacles in the mental health system and wider society is a hallmark of a recovery-focussed service⁴⁰⁴:

When such obstacles are encountered on an individual's pathway to recovery, it is the job of the guide to work in collaboration with the client to identify the roadblock and to find routes under, around, over, or through it. This might mean encouraging the client to challenge the 'rules' by becoming active in the agency's or the system's various decision-making bodies . . . or becoming active yourself.

(p. 497)

One approach is to engage with people outside the clinical context. An example is the trialogue initiative in German-speaking Europe, described in our final case study.

Case study 26: Trialogues

An innovative approach to changing community and clinical attitudes to mental illness is the Trialogue initiative⁶³⁴, also known as Psychosis Seminars⁶³⁵. These have been held in German-speaking countries since 1990. A Trialogue group involves users, carers and mental health workers meeting regularly in an open discussion forum on neutral territory, away from any therapeutic, familial or institutional context. The aim of these meetings is to learn from each other, by discussing the experiences and consequences of mental health problems and mental illness and different ways of responding. Patients who attend are more likely to be critical of current services, and one important motivation to attend is to be actively involved and initiating change in the way mental health care is practised. Family members tend to feel under-supported by services, or live with a consumer who does not willingly accept any treatment. Their motivation is to increase their knowledge about the illness and to share their feelings and learning points with others. Professionals who attend tend to be more senior and are motivated by a desire to reflect on their own practice and learn about psychosis processes.

The groups also lead to initiation of activities, such as serving on quality control boards and a trialogic day in the training of police officers about interacting with people with mental

Case study 26: (cont.)

illness. Over 130 regular Trialogue groups are now attended by approximately 5000 people. Trialogues are inexpensive, widely seen as beneficial, and have developed concepts and terminology which differ from a biomedical model of mental illness (which is still widely prevalent in the mental health system). Specifically, they provide an opportunity to interact outside role stereotypes, and a learning forum for working together on an equal basis – as ‘experts by experience’ and as ‘experts by training’.

Further information: michaela.amering@meduniwien.ac.at

We have identified seven key actions for organisations wanting to develop a focus on personal recovery. We end by looking ahead.

The future

Developing a focus on recovery will be resisted by parts of the mental health system. Personal resistance will arise because of the risk to job security (can I do what is being asked?) and role security (do I want to do what is asked?). Failure is likely with any change – Samsung’s motto is ‘fail often to succeed often’ – and the need to expose oneself is anxiety-provoking for the individual and the organisation. A recovery approach challenges fundamental assumptions about the purpose of mental health services³³³:

The new paradigm also changes the nature of solutions and remedies from ‘fixing’ individuals or correcting their deficits to removing barriers and creating access through accommodation and promotion of wellness and well-being . . .

Simultaneously, the source of intervention moves from predominantly mental health professionals and clinical/rehabilitation service providers to that of fully incorporating social capital development, mainstream health providers, natural supports and peer / consumer advocacy, information and support services. Most important, the role of the person with a psychiatric disability shifts from being the focus of an intervention to one of a customer, empowered peer, and decision maker.

(p. 18)

This clearly involves more than the incorporation of new ways of working into mental health services. Working in ways which support recovery will, for example, require a different professional identity⁶¹⁹:

A dramatic paradigm shift which fundamentally alters the ways in which professionals, individuals, families, and the community behave and interact is necessary . . . We must work together to move away from ‘medical necessity’ toward ‘human need,’ away from managing illness to promoting recovery, away from deficit-oriented to strengths-based, and away from symptom relief to personally-defined quality of life. Perhaps most critical is the fundamental shift in power involved in realigning systems to promote person and/or family-centered planning—the shift away from prioritizing ‘expert’ knowledge over respect for individual autonomy and self-determination

(p. 4)

There are already signs of active professional resistance to this direction of travel⁶²⁶. Evolving towards a recovery vision may prove impossible without fundamental transformation – a paradigm shift. Although challenging at the time, changes in paradigm are a healthy sign. Kuhn proposed that ‘Successive transition from one paradigm to another via revolution is the usual developmental pattern of mature science’⁶²⁷ (p. 12). This book has

argued that the process of recovery is far more wide-reaching and long-lasting than getting rid of symptoms, restoring social functioning, avoiding relapse and the other preoccupations of the current paradigm. Therefore, arguing for a focus on personal recovery is arguing for a paradigm shift, in which:

- previous preoccupations (e.g. risk, symptoms, hospitalisations) become seen as a subset or special case of the new paradigm
- what was previously of peripheral interest (i.e. the patient's perspective) becomes central
- the intellectual challenge emerges from outside the dominant scientific paradigm (the understanding of recovery emerges from people who have experienced mental illness, not from mental health professionals).

A reversal of some traditional clinical assumptions is at the heart of a recovery approach. Mental illness is a part of the person, rather than the person being a mental patient. Having valued social roles improves symptoms and reduces hospitalisation, rather than treatment being needed before the person is ready to take on responsibilities and life roles. The recovery goals come from the patient and the support to meet these goals comes from the clinician among others, rather than treatment goals being developed which require compliance from the patient. Assessment focusses more on the strengths, preferences and skills of the person than on what they cannot do. The normal human needs of work, love and play *do* apply – they are the ends to which treatment may or may not contribute. People with mental illness are fundamentally normal, i.e. like everyone else in their aspirations and needs. They will over time make good decisions about their lives if they have the opportunity, support and encouragement, rather than being people who will in general make bad decisions so professionals need to take responsibility for them.

The Personal Recovery Framework of [Chapter 9](#) provides one way of understanding the processes involved in the central recovery task of reclaiming identity. It is superordinate to clinical models of mental illness, which provide explanatory models for the 'Mental illness part' of the framework. It is in this sense depicting a paradigm shift, in which the previously dominant clinical models become seen as a special case in the new paradigm. This is more than a change in rhetoric. As John McKnight put it⁶²⁸: 'Revolutions begin when people who are defined as problems gain the power to redefine the problem' (p. 16). A genuine shift in power is involved, with the priorities of the consumer moving to a position of central importance. If power remains held within the mental health system, then recovery will simply be the latest thing to do to patients. As Bracken and Thomas put it²⁶:

Insofar as citizenship is inextricably tied to democracy and human rights, it is not within the 'gift' of professionals. It is, perhaps, just as paternalistic for mental health professionals to say to service users 'Look! Here is citizenship. Take it! It is good for you. It will liberate you' as it is for them to say, 'Look! Here is Prozac. Take it. It will make you feel better.'

(p. 254)

This book has tried to translate the consumer-developed idea of recovery into the clinical world. This aim is a stepping-stone to a more distant goal of there being no 'other'. Some of the steps along the way have already been taken, with service users having an increasingly audible voice, and a recognition of the need for user involvement. The next step may be the change from involvement (clinicians choosing to involve service users in decision-making) to partnership (needing the person to be involved). This will involve the deep transformation of coming to see the person with mental illness as part of the solution, not part of the