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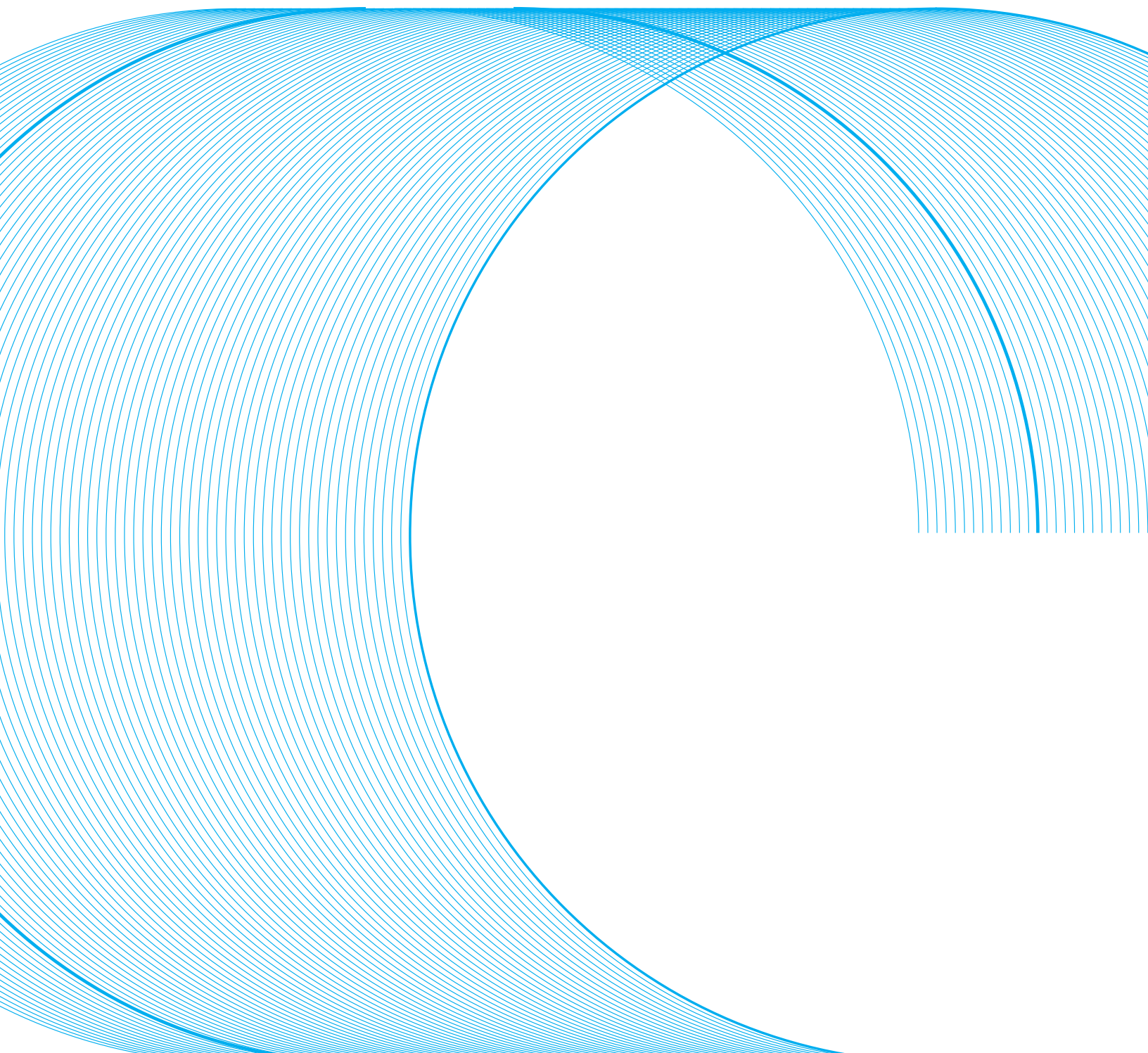
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# Treatment and Supports Summary

Narrators' experience of diagnosis, treatments and services varied widely. Diagnosis provided liberation and explanation for the way people felt or behaved, but it also served to stigmatise and categorise people into a set of expected symptoms. It gave some hope and made others despondent, it provided access to treatments and services, and income maintenance entitlement, but some people felt that it excluded them from work and mainstream society due to stigma and low expectation for recovery. The way in which diagnosis was initially shared was important. If delivered with information and an optimistic message for recovery, reactions were more positive.

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# Treatment and Supports Summary

**There was a perceived lack of control over access to supports and services. Service gaps were noted by narrators but also noted was a rationing of services by diagnosis and illness severity. Continuity of supports (personnel and service) and flexible support systems expedited recovery.**

Different responses to medication were provided by narrators. Some felt that their recovery was enhanced by finding the right medication. Others felt that their recovery could be measured by the fact that they no longer considered medication necessary. Side effects, available alternatives, trial and error in finding a suitable effective drug and a desire to be medication free affected decision to take to prescribed medications.

Supports and services provoked both positive and negative responses from individuals. It is obvious that individuals received different levels and types of support often depending upon the knowledge of the person making the referral and the types of supports available in their area. Treatments that were favoured by narrators included Cognitive Behavioural Therapy (CBT) and other talking therapies.

Professionals noted as having a large impact upon recovery included psychiatrists, psychologists, counsellors, community psychiatric nurses (CPNs), social workers, support workers and occupational therapists. Indeed, finding the right professional to work with could provide a significant turning point, helping individuals navigate their own recovery journey.

Housing support, often serving transition periods from hospitalisation to community resettlement, was discussed by narrators who found it to be beneficial, easing the difficult process of reintegration with their community. Additionally, the security to be found in having a 'home' where one 'belonged' was found to be a great source of contentment.

Financial supports in the form of various income maintenance benefits provided much needed financial security and a safety net to those who were not independently financially secure. However, difficulty in accessing benefits, eligibility and entitlement issues, stigma of benefit receipt, fear of withdrawal of financial supports and limited knowledge about 'rights' as a recipient made the support from these income benefits less consistent.

Good supports were described by narrators as:

- Taking a long term view of recovery and support needs.
- Mapping out recovery plans and monitoring progress collaboratively with the person concerned.
- Helping people move forward and reflect on their every achievement, building confidence and motivation.
- Not withdrawing support too early and offering long term support to maintain recovery.
- Incorporating self referral processes.
- Not keeping unnecessary notes on people and having clear practices about information sharing.
- Asking what support people would like and recognising that requirements are not fixed but change over time and with circumstances.

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- Listening and responding to what people want, non-judgementally and respectfully.
  - Treating people as individuals, offering support at a pace that suits them and offering choice in who people work with, providing choice in therapies and treatments.
  - Being proactive and sensitive to changes.
  - Being observant – notice when medication is not working.
  - Allowing individuals to determine when they no longer need support.
  - Providing ongoing links to external support organisations.

Current support services were described as needing to be more:

- Consistent.
- Organised, and on time.
- Open, listening and supportive.
- Flexible in service provision and availability.
- Trained in counselling, confidence building and mental health.
- Non judgemental.
- Observant – noticing when someone is in trouble.
- Prepared to engage with the bigger picture of someone's life and history.
- Supportive and knowledgeable in dealing with practical issues like benefits (finances) and housing.
- Focussed on recovery – not the illness.
- Empathetic and motivating.
- Proactive – not requiring the person to assert himself or herself to get support or attention.

# Treatment and Supports

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Previous chapters of this report detailed areas of internal and external change that could affect recovery. We explored how developing a positive confident identity and having meaningful relationships and activities in life were all factors that individuals could focus on to support their own recovery journeys. Whilst we primarily focussed on the individual in previous chapters, we must recognise that recovery is a journey that often requires support from formal services as well as from friends, families and colleagues.

# Treatment and Supports

**This chapter is focused upon individuals' experiences of accessing treatment and supports and on the issues narrators feel are important to ensure these services are oriented around recovery.**

In this chapter we investigate diagnosis and medications, and cover traditional and non-traditional therapies, and we look at hospitalisation, transition from hospital, perceived service gaps and professionals' attitudes. We also look at community services, finance and housing.

We begin by briefly acknowledging the current relevant literature before providing findings from narrators' interviews about their experiences of and perspectives on these supports and their impact on recovery. We will reflect on what factors narrators feel are important in ensuring that treatments, practice and services are recovery-orientated and conclude by considering briefly the implications of these findings for mental health policy and practice in Scotland, with some observation about the potential for recent policy developments to advance the realisation of a recovery-oriented mental health system.

## Diagnosis

The criterion for categorisation of mental illness has varied according to political and economic trends and has been reflective of shifting community attitudes and values. Even the criteria of symptoms for assessing the 'right to confine individuals' expand and contract depending on political climates (Bassman, 2005; Foucault, 1988). Whilst it has been argued that diagnosis provides clinicians and clients with a useful means for describing different manifestations of mental illness giving an indication of symptoms, expected course, treatment and prognosis, some who have explored the diversity of experience and the human context of mental illness, have increasingly called for an end to 'classificational diagnosis' (Marsh, 2000).

Crepaz-Keay has argued that diagnosis is at best unnecessary and at worst potentially damaging as it can lead directly to discrimination and a negative re-focus for personal identity, ignoring environmental factors that can affect illness. He and others (Bassman, 2005; Crepaz-Keay, 2003) have argued that diagnosis can facilitate discrimination and – controversially – its only real value is to those looking to profit from treatments for conditions. Crepaz-Keay argues that people would be better served by a 'comprehensive assessment of need' than an 'off the peg' diagnosis.

It has been argued that because psychiatric diagnoses (particularly psychosis and schizophrenia) are associated with negative societal reactions, they only exacerbate the course of a person's disorder (Link *et al.*, 1999; Phelan *et al.*, 2000). Diagnostic classification can potentially act to intensify stigma by enhancing perceptions of 'groupness' and 'differentness' when perceiving people with mental health problems (Corrigan, 2007). Also, having a diagnosis may encourage the public to perceive individuals in terms of their diagnostic label thus exacerbating the notion that people with mental illness do not recover. The idea of inevitable inexorable decline after diagnosis has, according to Lester and Gask (2006) become increasingly challenged by an emerging evidence base from long-term follow-up studies suggesting that approximately half the people diagnosed with a psychotic illness have a favourable outcome (Dorrer, 2006; Harrison *et al.*, 2001).

Contrary to these arguments, receiving a diagnosis has been suggested to give hope to some people by providing an explanation for feelings, thoughts and behaviour that have otherwise been difficult to comprehend. In addition, diagnosis can, for some, provide opportunity

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to seek out similarly experienced individuals and share coping strategies, and to provide information about an expected course of illness.

The debate over significance of diagnosis and its consequences remains unresolved and it is obvious that researchers, professionals and service users remain fractured in their opinions of whether receiving a diagnosis is positive, negative or unnecessary.

## Service gaps

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The treatment of mental health problems has been found to be complicated by gaps in service, including restrictions on the ability of primary care to refer to mental health specialists. This often causes service users to experience the mental health system as compartmentalised, uncaring and fragmented.

Prior to the introduction of the Mental Health (Care & Treatment) (Scotland) Act (2003), Dr Sandra Grant consulted with service users, carers, NHS bodies, local authorities and the voluntary sector in order to undertake a comprehensive assessment of existing mental health service provision in Scotland. Reviewing available evidence about the organisation, management, efficiency and effectiveness of these services, she identified gaps or duplication in the provision of services in order to consider how the range of facilities could meet the objectives of the new Mental Health Act. She found that although the new Act was welcomed, there would be difficulties in implementing it and significant changes and developments would be needed, including arrangements for:

- 24-hour crisis and support services.
- Joint community mental health services.
- Access to appropriate hospital facilities for all.
- A range of daytime activities, talking therapies, help with employment and support people recovering from mental illness.
- Providing more information about rights and treatment, and being treated for without consent.
- Agreement on the way forward for staff planning and training.
- Independent advocacy (Grant, 2004).

Foreign studies investigating access problems and service gaps have been numerous. Although the services investigated in these studies have different structures, cultures and accessibility criteria to Scottish services, it is interesting to note the problems they demonstrated.

Communication and follow-up between referring agencies and treatment providers and continuity of caregiver was found to be lacking in Onken *et al* (2002) and Raingruber (2003). Similarly, Tondora and Davidson (2006) found disconnected care offered by different providers to be damaging to recovery.

## Medication

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The most recent survey of public attitudes to mental health in Scotland (Braunholtz *et al.*, 2007) reported that 35 per cent of respondents (for whom the question was relevant and who expressed an opinion) felt that medication had been one of the most important factors in supporting their recovery. A survey by SAMH (2004) found that over half of their respondents found their prescribed medications to be helpful in spite of the fact that many people experienced unwanted effects. However, in this study people's experience of individual drugs

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was found to vary considerably and finding the right drug was largely considered a question of trial and error.

Issues in medication that researchers have found to be contentious have historically concerned prescribed medication management, adherence to prescription, the right to self-medicate and side effects of medications. Some writers are challenging the negative language of 'compliance' and now talk of 'concordance' with medication which suggests more a process of negotiation than instruction and obedience.

Despite documented studies pertaining to the effectiveness of psychiatric medication, many studies reveal that consistently high numbers of individuals (between 29% and 50%) do not take their medications as prescribed (Roe & Swarbrick, 2007; Sirey *et al.*, 2001; Zygmunt *et al.*, 2002). Consistently poor follow through with care, patient attitude (asserting control or preference (Munich, 1997)), paternalistic treatment systems, side effects of medications, psychiatric symptoms (Mancini *et al.*, 2005), stigma, and denial of illness (Sirey *et al.*, 2001; Weiden *et al.*, 1997) have been advanced as reasons for non concordance to medications. Additionally, those who perceived taking medication as a threat to their freedom of choice are less likely to have taken it as prescribed.

Hamilton Wilson *et al* (2005) argue that honestly discussing the limitations of medication is important when asking people to adhere to prescribed treatments.

Various programmes have been developed in an attempt to increase concordance to pharmacological treatments (like psychoeducation/family therapy, and cognitive behavioural treatments), and have shown mixed results in meeting their aims. Roe and Swarbrick (2007) suggest that if non-adherence is to be perceived as a problem, exploring the meaning of and reasons for it within the context of the service user's life may facilitate understanding.

Deegan and Drake (2006) have argued that compliance with medication management is an inadequate construct that fails to reflect the conflicts individuals must face in managing their wellbeing. Seeing compliance to be at odds with the principles of person-centred care, they and others (Mueser *et al.*, 2002) argue that 'shared decision making' between professionals and clients to collaboratively determine the optimal treatment is a better means to negotiate treatment and medication plans.

According to Fisher (2003b) helping relationships, including psychotherapy, play a much more important role than medications in recovery and this is routinely suppressed by the pharmaceutical industry.

## Hospitalisation & transition

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Hospitalisation can often result in feelings of powerlessness, especially where in certain circumstances, doctors have a mandate to treat against the will of patients and where individuals lose the right to make decisions. Indeed, the loss of self-determination was construed by some Highland User Group members to be a 'punishment' for individuals when compelled to receive treatment under the Mental Health Act (HUG, 2005). Also, research on the living conditions on acute wards has suggested that they are 'non-therapeutic' and not necessarily conducive to recovery or getting people well.

Although various studies have shown the benefits and negative impacts of hospitalisation (involuntary or voluntary) on recovery, studies dealing with transition from hospital have more often found services lacking in coordination and accessibility (e.g. resettlement, housing,

personal care, socialisation services).

From a Scottish perspective, Highland User Group members expressed both elation at the prospect of returning home and anxiety and trauma about being discharged from hospital (HUG, 2003). Some individuals consulted felt disempowered with no involvement in their discharge, some indicated that there was a lack of preparation and found the abruptness of the discharge process to be very disconcerting. Income maintenance (finances), housing and tenancy issues, difficulty reintegrating into the community were amongst the numerous challenges individuals faced during transition from hospital (HUG, 2003). Similarly in the US, Beal *et al* (2005) and Liberman and Silbert (2005) identified that important dimensions of community adaptation for persons with serious mental health problems are usually missed by mental health professionals.

Coordinated inpatient and community treatment, long considered a necessity is far more the exception than the rule. For individuals with serious mental health problems, leaving the predictable, safe, secure, and supervised setting of a psychiatric hospital is a challenging transition.

## Recovery-oriented service systems

Several studies have identified or developed frameworks for recovery-oriented services. Anthony (2000) assessed that a recovery-oriented service is constructed upon and grounded in the idea that people can recover from mental health problems. This revised service orientation demands a new response from services and professionals, a response which is positive, respectful, facilitating and empowering.

As an alternative to traditional professional-based services (where professionals are assigned responsibility for clients), some people have advocated for recovery-oriented self-help and peer-based services which offer a non-hierarchical system of service delivery (Mueser *et al.*, 2002).

Mosher (2004) identified several factors that are predictive of a positive outcome in recovery-oriented psychosocial programmes, including the presence of a healing context (hospital unit, peer resource centre, community based recovery-oriented team), a therapeutic culture, an expectancy of recovery, opportunities for experiencing success, and the reassurance of confiding relationships with helpers.

Alternatives to traditional mainstream psychiatric practices that embrace values as evidence alongside purely empirical evidence are increasingly being adopted in services and by a range of professions (Allott & Loganathan, 2002). Recovery focussed frameworks such as the Tidal Model (Barker, 2003) promote the intrinsic value of personal experience in the development of personally appropriate mental health nursing care.

## Professional's recovery orientation

It is extremely encouraging that a range of professional bodies are now making explicit their commitment to recovery and to values based practice.

With the publication of *Rehabilitation and Recovery Now* (Cope *et al.*, 2003), the Royal College of Psychiatrists describe the opportunities for psychiatrists to develop new recovery-oriented skills throughout their careers, suggesting that recovery may begin to play a larger

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role in the philosophy and approach of psychiatrists in the future. More recently the college published a joint position paper with Care Services Improvement Partnership (CSIP) and the Social Care Institute for Excellence (SCIE) confirming a solid commitment to a recovery approach (CSIP, 2007).

Whilst work to orientate stand-alone mental health services in recovery have progressed in Scotland, some allied services appear to be in their nature recovery oriented. Gruhl (2005) suggested that occupational therapy (OT) should take a keen interest in the construct of recovery because core occupational therapy beliefs and assumptions are strikingly similar to those purported to be important to fostering recovery. Occupational therapy is often identified as a profession that focuses upon client strengths and abilities, and in the past OT research has focussed upon self-esteem, self-efficacy, empowerment, self-determination and quality of life (College of Occupational Therapists, 2007a). Despite these similarities between the recovery paradigm and occupational therapy research, little research has been published about the role of occupational therapy in promoting recovery. However, the College of Occupational Therapists in a recent document (2007b) placed recovery and hope along with crisis and compulsion as the two alternative approaches to service delivery and practice.

Occupational therapy is seen by the College of Occupational Therapists in the UK (2007a) as essential to the delivery of social and psychological recovery in people's lives.

Parallel to the increase in recognition of OT as a potentially recovery-oriented service, several researchers (K. M. Berzins, 2005; Carpenter, 2002; Stromwall & Hurdle, 2003) have articulated consistent similarities between empowerment based social work practice and psychiatric rehabilitation or recovery as they both focus on and emphasise skills building, self-determination, empowerment, successful adaptive community functioning, social support, and active self management.

## Psychosocial interventions

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The most recent survey of public attitudes to mental health in Scotland reported that twenty per cent of individuals (for whom the question was relevant and who expressed an opinion) indicated that non medical forms of treatment or therapy (talking therapies, counselling, alternative therapies, support groups) had been one of the most important factors in supporting their recovery (Braunholtz *et al.*, 2007).

The basic goal of psychosocial treatments (like family therapy, CBT, vocational rehabilitation, psychoeducation) is to improve individuals' resilience, coping resources and system supports to protect individuals against environmental stressors, thus facilitating recovery (Beebe, 2007).

There is evidence that supports the effectiveness of psychosocial interventions. Mueser *et al.* (2002) in their literature review of illness management strategies found that coping skills training using cognitive behavioural techniques reduces the severity and distress of persistent symptoms. Cognitive behavioural strategies have also been used to help people learn how to manage their mental illnesses more effectively.

A consistent finding across studies (Mueser *et al.*, 2002) has been that cognitive behavioural treatment is more effective than supportive counselling or standard care in reducing the severity of psychotic symptoms. Furthermore, studies that assess negative symptoms, such as social withdrawal also report beneficial effects from cognitive behavioural therapy on these symptoms. Zygumunt (2002) in a systematic literature review (of texts between 1980 and 2000) examined psychosocial interventions for improving medication adherence and found that

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although psychoeducational approaches were common in clinical practice, they were typically ineffective. Interventions targeted specifically to problems of non-adherence were more likely to be effective (55%) than were more broadly based treatment interventions (26%).

## Recovery competencies and relationships

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Research on psychological interventions attest to the singular importance of the therapeutic relationship irrespective of the type of therapy offered. The importance of relationships in all aspects of care and treatment and in maximising the effectiveness of interventions and treatments is widely recognised.

Schinkel and Dorrer (2006) in their recovery competencies research found that despite positive examples of helpful relationships, service users and carers consistently pinpointed unhelpful relationships with mental health workers (especially more powerful professionals such as psychiatrists) as one of the main obstacles to recovery in Scotland. Watkins (2007) argued that *“there is a need to remove a prevailing sense of hierarchy from the helping relationship in favour of collaboration and client autonomy.”* This has added voice to the growing call for professionals to be able to engage with individuals in a way that values and seeks to understand their perspective in a person-centred way, putting hope, optimism and social inclusion at the centre of any treatment plan (Berzins, 2005; Deegan & Drake, 2006; Hamilton-Wilson *et al.*, 2005; Sells *et al.*, 2004).

In their study of service user perspectives of recovery-oriented professional relationships, common helpful factors were identified by Borg and Kristiansen (2004). Service users valued professionals who conveyed hope, shared power, were available when needed, were open regarding the diversity in what helps, and were willing to stretch the boundaries of what is considered the professional role, supporting individuals in their own ways of dealing with problems and struggles. Braunholtz *et al* (2007) found that mental wellbeing was related to the extent to which professionals (and friends and family) provided a positive or negative message of recovery potential. Indifferent professionals could adversely impact recovery whilst the existence of supportive relationships were identified as influential in facilitating recovery in Mancini *et al's* (2005) study of how individuals recover from serious mental health problems.

(For a list of recovery competencies see: O'Hagan (2001) and Schinkel and Dorrer (2006).

Recovery from severe mental illness has become an increasingly relevant concept in the mental health field (Schrack & Amering, 2007; Schrank & Slade, 2007). Recovery-oriented practice builds upon the strengths and resources of individuals enabling them to deal actively with mental health experiences rather than being given 'supports' by mental health services in a passive model of rehabilitation. It allows professionals to use their skills and expertise in a collaborative partnership with service users (Borg & Kristiansen, 2004).

## Other Supports

### Housing and transition

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Appropriate, affordable and safe housing is arguably an essential component of any citizen's life. The need to have somewhere suitable to live is crucial for individuals to gain or retain any sense of community and independence, but having your own accommodation can be daunting as well as liberating for individuals in recovery from long term mental health problems.

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Leaving the nurturing and supportive environment of the hospital can be difficult for many, however, Cleary (2003) in his ethnographic study of the way mental health nurses interpret their practice in acute inpatient facilities (in New South Wales, Australia) found that it is disheartening for individuals to be in acute inpatient settings on a long term basis when waiting for suitable accommodation for discharge.

A major goal of a recovery-oriented housing system according to the Canadian South West Mental Health Implementation Task Force (2002, p.17) is to ensure that housing options respect and support individual need and preference. Support in retaining housing is often missing from mental health programmes. The New Zealand Mental Health Commission (2001b, p. 2) found that persons with mental health problems can lose their homes for various financial, social and cultural reasons during extended periods of illness. They also found that having a safe and secure housing environment, a 'home' can *"contribute significantly to identity and self-esteem as well as providing a base in the community."* This emphasises the need not only to ensure people are supported to attain suitable housing, but also where applicable, that they are supported to retain the tenure of the home they reside in.

## Financial supports

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A major practical support to recovery is the support found in financial security. Some individuals with severe mental health problems who are in receipt of income maintenance benefits (e.g. Disability Living Allowance, Incapacity Benefit, tax credits) expect to remain on these benefits for the remainder of their lives and view them as a security blanket (Highland Users Group, 2006a, 2006b). It is known that many people who have severe mental health problems are economically inactive and are on incapacity related benefits (Government, 2005; Social Exclusion Unit, 2004). Also, the longer a person is away from their job, the more difficult and stressful a return to work can become as people often suffer a great loss of confidence. So it is obvious that having adequate financial support to ease the loss of wage (where applicable) is essential to supporting many individuals.

Research conducted by the Chartered Institute of Personnel and Development, published by Poverty Alliance emphasised these difficulties, finding that 55% of employers would not, under any circumstances, recruit those claiming incapacity benefit, with 60% admitting to disregarding applications from people who claimed it (Big Issue, 2006; Chartered Institute of Personnel and Development, 2005, 2006). Therefore, although there is a clear link between financial security and wellbeing, the reality is that people with experience of severe mental health problems can and do face enormous barriers in accessing work as a means of securing an income (See Engagement chapter).

# Treatment and Supports Findings

In this chapter we investigate numerous external supports and treatments that can affect recovery. We look at diagnosis and medications, traditional and non-traditional therapies, hospitalisation and transition from hospital, perceived service gaps and professionals' attitudes. We also look at community services, and how finance and housing issues can influence states of wellness. Findings from this chapter reflect numerous experiences of hospitalisation and service use. However, we did not always know how recent people's experiences of these services were and recognise that practice may have improved over time.

## Primary care

Primary care and general practitioners (GPs) were generally the first point of call for our narrators when experiencing mental health problems. They were called upon for practical issues such as getting a 'sick line' and accessing medication to manage their symptoms. GPs were said to support people to manage prescribed drugs and help them to understand and navigate around the mental health system. Several were said to be very aware of mental health issues and where to refer people on to.

**"I know the stories about GPs who have got no time for people with mental illness and eh... you know, I've heard stories about that, but I must say I'm terribly fortunate in so far as my own GP is exceptionally, eh, sympathetic and eh... to people with mental health problems, you know? Lucky!"**

**"I feel that my GP was a great help, she really listened and understood, monitored my medication very well I feel. She referred me to the right people, the psychiatrist and psychologist."**

Where GPs were perceived to offer good support they were said to:

- Be very supportive about all aspects of life not just illness.
- Give the time to listen, allowing people to open up.
- Give opinions on the situation.
- Take time to explain things properly.
- Push people in their recovery.
- Have had a consistent relationship with people over many years.
- Refer people on to appropriate services.
- Provide counselling within their practice.
- Be available.

Some individuals had experienced GPs as unhelpful, but due to the procedural nature of the NHS they still had to be seen in order to access other services, benefits and support. They were said to know too little about mental health to be useful in diagnosis, counselling or recommending appropriate treatments and to have too little time to deal meaningfully with mental health issues. Most often narrators complained that they tended to rely too heavily on medication.

**"Well my doctors... I've been on eight different anti-depressants in the past five years, and, as I said before, some of the side-effects are horrendous... That's what I feel with doctors... I go out the door and four months later or four weeks later, I'm (through) their door again and I'm sitting in front going through it all. It's just like a record. And you begin to doubt the confidence in yourself, because you say 'what kind of human being am I?' I'm trying to justify myself being ill to**

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**a point, to being well, but this final step to total recovery disnae seem to be there – you’re always grasping for it. So doctors are kind of helpless as well.”**

**“GPs, when you have been mentally ill and they’ve got it all in front of them they think that your physical symptoms are probably imaginary.”**

Some people felt that GPs should have at least the same knowledge as a CPN to be useful in dealing with mental health problems.

## Diagnosis

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Diagnosis had been a double-edged sword for many. It has provided affirmation in the minds of some individuals, confirming that there *was* something wrong, opening doors for services and treatments restricted to the ‘mentally ill’, helping to identify signs and symptoms could be managed or controlled with suitable treatments. However, it had also frightened individuals who perceived diagnosis as something that potentially branded them with a categorical label that led to stigma and a lifelong sentence of ill health.

**“Two to three years ago I realised that you really could recover... ‘Cause I thought once you had it that was it – it was stuck, but you can recover. I find that quite an amazing fact, cause over the years psychiatrists and things, no one actually says ‘you can recover’ it’s never mentioned.”**

## Feeling informed and in control

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A large number of narrators found that getting a diagnosis made them feel more in control of their situation. Once they had a named illness they could embark upon learning more about their illness, researching symptoms, treatments, medication and side effects, and could relate this to their own experience. Describing the diagnosis as **“a big step forward”** as they accessed treatment and support, narrators felt more secure and better equipped to engage and deal with both illness and recovery. They describe being given a diagnosis as leading to a **“thirst for knowledge,”** especially where diagnosis had been delayed, sometimes even from childhood. Without a diagnosis some narrators felt ill-informed and unable to research and understand what was happening to them.

Individuals described a sense of relief on receiving a diagnosis. The confirmation it provided was often needed in social, work and finance-related (social security and welfare benefits) settings to convince other people of the reality of their situation. A named illness, a diagnosis, provided the necessary proof.

Receiving their diagnosis also enabled individuals to learn from others who had coped with receiving and living with a similar diagnosis. They could access self help groups for people with similar issues which enabled them to learn from a range of experiences across a spectrum of different people.

**“Well the main thing, initially... especially on diagnosis, was learning about the illness... I tended to attend self help groups... and I suppose I just found it helpful that, surprise surprise, I’m not the only one with manic depression... I’m hearing their stories, their experiences and relating really, really well to them... So I found it a very refreshing way to learn about my illness... I think it was just my thirst for knowledge for what was up with me.”**

One narrator stated that their diagnosis showed them that they were a special person, not like 99% of people in the world.

**“Psychotic episodes... only one in a hundred have these experiences, it’s a rare condition. And this is a point I want to get across because you turn that statistic round and 99% of the world’s population do not have psychotic episodes. What does that tell you as a researcher? It is a rare phenomena.”**

## Diagnosis withheld

Several individuals considered that not knowing their diagnosis had delayed in their preparation for developing management strategies. Whilst few questioned why their diagnosis had been withheld, one narrator reported finding out their ‘serious diagnosis’ by chance when their medical certificate was *accidentally* left out by their doctor.

**“I had never even been told my diagnosis. I found them out from when I got a medical certificate from my GP. So it was a bit of a shock when I came out of a GP one day and read my... ‘paranoid schizophrenia’ – what?”**

**“I got a late diagnosis and it caused quite a lot of concern, well a lot of upset and chaos... hearing about people... or learning about what triggers... learning about early warning signs, what some of the traits of the illness were. That armed me to form a sort of self management style for myself.”**

Concerned individuals implied that if psychiatrists had been more open-minded about openly diagnosing their illness, it would have helped them access the right treatment sooner. These individuals expressed concerns that they had dealt with the symptoms of their illness from childhood and had never understood that they were ill until they received their diagnosis. Accordingly, some narrators expressed bitterness towards GPs who had been treating them since childhood and had not recognised the symptoms or had not acknowledged that they were ill.

**“I went to see a lot of GPs with depression... since I was at school, and nobody picked it up. I would have liked to be looked into a bit harder that’s what I think. If I got the treatment earlier and the understanding earlier I could have felt like this earlier (i.e.: better) and I wouldn’t have kind of lost 20 years.”**

For some narrators, it took years in and out of hospital before they were given what they considered to be the correct diagnosis, support and treatment.

**“I didn’t get any psychiatric diagnosis until at least fifteen years later when... I was sectioned...”**

Using diagnosis as means of controlling access to services was found to be unhelpful, but not uncommon.

**“The indication was... you know, kind of implying that if you ever get diagnosed as having had psychotic episodes then you’ll get help, and there’s things and that there for you, and if you don’t, if that doesn’t happen, em, you know there’s nothing there for you, but we’re here for you.”**

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## Diagnosis and alcohol use

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A few individuals who were dealing with alcohol problems found the diagnostic system and assumptions made by service staff particularly unhelpful. Met with unsupportive attitudes, lack of understanding and judgement, they were often told that their alcohol habit was at the root of *all* their problems. All narrators concerned were finally acknowledged as having mental health problems that they exacerbated by alcohol abuse rather than mental health problems caused by alcohol abuse. Once it was recognised that the narrators used alcohol as a coping mechanism for ongoing mental health problems, negative attitudes subsided and they accessed the help they needed to deal with their mental health problem and to develop less destructive coping mechanisms.

**“I used to get terrible discrimination... staff looked down their nose at me and treated me like I was a piece of shit, but see now... they’ve accepted that it wasn’t just drink.”**

**“I’d spent years arguing with professionals that I drank because of my mental health, I don’t have mental health problems because I drink.”**

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## Negative impact of a diagnosis on recovery

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Individuals narrated their struggle to get a diagnosis and their problems with changing diagnosis depending on who and where they were being treated. Many described being given an unfair diagnosis or having been given a vague or complicated diagnosis that has hindered their ability to comprehend their situation and recover. This led to a level of cynicism regarding the diagnostic process.

**“You’re re-diagnosed on average every seven years, um, so I’m due for another diagnosis.”**

**“Wrong diagnosis is just a, it’s something you have to accept. Misdiagnosis. Um, the way services are geared, services are geared towards care and containment. You know, and to make you not a danger to the public.”**

Wrong (as well as correct) diagnosis has sometimes resulted in being prescribed medication that has made individuals ill. Even where people knew their diagnosis was wrong they often felt powerless or too ill to challenge it. Negative attitudes, misdiagnosis and delays in diagnosis have hindered people’s recovery and in some cases led to a lack of faith in the entire psychiatric system. Hence, a large number of narrators (equal to those that felt it assisted their recovery) felt that having a diagnosis actually hindered their recovery.

**“It’s the word, it’s the diagnosis: manic depression. As soon as you hear ‘manic’ you think, oh boy... it says ‘insane’. Basically it says that you’re insane or whatever.”**

Several narrators described feelings of rejection and a lack of support at the time of receiving their diagnosis and that this had a negative impact upon them.

**“It was that psychiatrist... over the phone he said it was an informal chat... to begin with, and then he started telling me that he thought I was on the spectrum to manic depression. And I’m like ‘nobody’s ever mentioned this before’. So then he’s sort of going... like it could be your personality... To be told that you were on**

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**the spectrum to manic depression, and not to get a whole explanation; to be told over the phone!”**

Many felt that they needed help in order to come to terms with and be more informed about their illness, to allow them to take more ownership of it. This need for reassurance from professionals that their condition was treatable and that they had not been given a life sentence was evident, but it was often lacking. For some the negative feelings generated by getting a diagnosis persisted for years and made them feel as if they would never recover.

**“I was just having a formal diagnosis of what I thought at the time was a life sentence.”**

**“Uhm, it’s depression, anxiety, uhm, panic attacks, but the depression part, there is so many different kinds, nobody has actually said what kind of depression it is, ‘cause I swing up and down so fast... And I did ask one psychiatrist and she says ‘well really it all depends on who you see and their opinion...’ And I was reading books and things and I was getting myself more muddled... this is making me worse... trying to find an answer.”**

Several people describe not agreeing with or trusting the diagnosis they were given, they also describe feeling disempowered by it. Often in these cases, narrators expressed that having a diagnosis meant that the focus shifted to drug therapies and symptom management and away from seeking the cause of the illness and recovery strategies.

**“It goes back to people making decisions about me because I initially didn’t fit any clear category, so they assumed things that they shouldn’t have assumed, so assumptions have been a huge thing that’s counted against me.”**

## Access to and continuity of supports

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Narrators reported a lack of control over which professionals they work with and lack of control over the services they access. It was felt that GPs do not take the time to consult properly, some services send individuals away (even individuals at risk of suicide), and people who felt they needed hospitalisation were often denied it. Those that could afford went private, others had to wait or miss out.

**“I would have liked to have gone to a psychiatrist, but the GP was not at all for it.”**

Individuals felt that it is important to get access to services as soon as possible in order to recover but found themselves hindered by gatekeepers. Long waiting lists, bureaucracy and judgemental or unapproachable staff sometimes added to the barriers between individuals and necessary appointments.

**“I mean they’re not nasty people down at our local health centre, but they’re very able to tell you that all the appointments are booked, regardless of what kind of a state you’ll be in... they’ve been driven to quite a point of despair by being told that there’s no way they can get to see anybody for a long time.”**

**“...it’s really quite a barrier sometimes, getting past the dragon at the reception.”**

**“I was told when I was discharged that all I had to do was phone them up again if I ever felt I needed help from them. Of course when my husband tried to do that, um, it didn’t work!”**

Some individuals also felt that their recovery had been hindered as a direct consequence of not being considered ill enough to access support.

**“A big gap that I found was when I came from the unit and was home, there was a big gap, I don’t know, I’d all this support that had helped and then I was at home and I hadn’t got anybody. And I apparently wasn’t ill enough to have a... well that’s not actually true, I had had some psychiatric help from the doctor, like once a month, but then that finished and then I didn’t have anything and I felt, ‘Oh gosh, how I’m going to cope now?’”**

People who were told they should be seen by a psychiatrist were sometimes not seen for years. One individual lost access to a psychiatrist for over a year because he/she was not a *“continuing patient”*, another was referred to a service where the psychiatrist offered to help but failed to make secondary contact.

Another aspect that was said to hinder the recovery process was that *“you have to be really darn lucky to get the same doctor twice,”* so *“there is no chance to build any sort of relationship with anybody.”* This lack of continuity made it difficult for people to address complex issues with them since they had to try and establish trust and relationship at each session. It also resulted in the need to revisit difficult issues over and over – retelling the story of illness. In regions where resources were low, when a psychiatrist left a service, narrators found themselves stranded without a psychiatrist service for years. Six month waiting lists for first meetings with a psychiatrist often at a time of extreme illness was not uncommon.

**“One of my biggest bugbears with the whole system... not too far into the illness my doctor thought, I’ll get you to see a psychiatrist... and I ended up getting a letter saying that was about a six month waiting list and that was as much good to anybody as a chocolate fireguard. And they thought about counselling and that was a six month waiting list so really at the time when you needed the help, it wasnae there.”**

A few narrators reported having difficulty accessing talking therapies when they needed them. Time limited and restricted courses were often prescribed and were generally inflexible requiring individuals to fight for continuation when something was working for them. Some individuals reported that they were working with psychiatrists for many years before therapies that initiated their recovery journeys were offered. Finding counsellors who were not commercially driven and taking on the cost (financial and emotional) of searching for and trying out new counsellors was reported as problematic.

**“If there were, uhm, structures in place for people to access, uhm, counselling and access psychotherapy and cognitive behavioural therapy and psychosocial interventions and things of that nature, uhm... I think that would be really beneficial. And the only way you can do that is if you’ve got money, cause then you go to The Priory or something, if you are a celeb.”**

There was a clearly articulated need for more flexibility in support services, so that they are accessible day, night and weekends and can provide home support when people are ill.

**“You are not meant to take ill between five o’clock on a Friday and nine o’clock on Monday morning because there is nothing, absolutely nothing. Trying to get a doctor, trying to get a psychiatrist, or a doctor, or a nurse, there is nothing there, and I mean sometimes at the weekend that’s when people are more vulnerable.”**

The non responsive nature of most services hindered recovery for individuals.

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## Flexible support to recover

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An inability to cope with fluctuating illness was apparent in some services and a distinct lack of continuity of care was evident in many circumstances, especially where individuals approached new doctors or changed doctors. To enhance the recovery process, narrators suggested that services need to be more accessible and responsive to people's changing needs. Individuals do not always need continuing services but may need short timely interventions to keep them on track.

When people described support services that worked for them in their recovery they did not describe huge complex support packages but lighter touch, flexible, joined up or coordinated responses that offered choices.

**“Their approach was just amazingly different. They were actually offering it (CBT) to you, they weren't saying ‘Well what do you think you need,’ because you don't know... (They were) putting things in front of you and saying, ‘We think this could be beneficial, what do you think,’ and that made a big difference. They gave you a bit of choice.”**

In addition to this flexible response, individuals needed to know there was a concrete safety net, someone there if needed. This could be access to a key worker, or having the knowledge that there is a mental health team on the end of the phone who knows and understands their personal history, medications and circumstances.

**“Well I've got my occupational health people and I've got my CPN. And it's really just talking with my CPN and eventually the occupational health listen closely to my CPN and we'll work out a scheme through them. I mean, at the moment it's all very flexible.”**

**“I've got a place to go which is supportive, you know, and I know that if there is any trouble, you know, that I am feeling a bit down or whatever, then there are people there that I can talk to...”**

Community psychiatric nurses were cited as particularly good support workers by some, not only in dealing with mental health issues, but also in addressing more practical issues regarding finances, debts, benefits, housing, employment and living alone. Most narrators acknowledge that they could not have managed their recovery without professional help. However, having control over the who, what and when was an important aspect of an effective relationship with a professional. The role of CPNs in supporting the person to negotiate and manage relationships with a range of professionals was noted as pivotal.

**“I found having a CPN doing home visits was really helpful. Just knowing that you have got this connection. They can be a go-between between you and your doctors and if you are really unwell they can access help for you.”**

**“If you are lucky to have services like a CPN then use them and learn from them because what they say and do for you is very important. They can stop you getting unwell through support and encouragement, and for recognising when you aren't coping and need additional help.”**

The challenges highlighted in accessing flexible, responsive services in the community were key and were often related to periods of transition. When people moved from hospital to living at home, some individuals felt the drop off in support was too rapid. In hospital they had often been working with nurses to develop social skills and confidence and in planning their move

home. The drop in support was particularly hard felt if the person was part of group therapy in hospital.

Where individuals transitioned back to employment, there was a similar rapid loss of support reported when individuals were too quickly assumed to be coping.

For some, services were too fragmented and too quickly relinquished. It was felt that this did not reflect the recovery process.

**“Recovery comes and is a slow journey, and that’s where the services let you down very badly because they cannae support you through the whole journey and it’s a pity.”**

## Medication

Nearly a third of narrators indicated that medication was key to their recovery, some also described finding the right medication as the turning point from illness to recovery. Getting the right medication helped to alleviate symptoms and distress, and allowed individuals to focus on rebuilding their lives. It stabilised these individuals, allowing them to have the confidence that they could live symptom free and well and thus sustain their recovery.

**“There had been a slight change in my medicine and the tension episodes stopped and it was like sort of being reborn, it really was.”**

**“Most of the direct help has come from being put on the medication which just helps to deal with the symptoms and not coping with life afterwards.”**

Several people reported having been on medication since their first episode of illness and that they would not risk coming off it. Others have tried to reduce dosages and come off them but found that they become unwell again.

**“The medication became unfortunately a medication that I had problems coming off of and I had side effects coming off it and that was a nightmare.”**

Some people felt that an over reliance on long term drug interventions was not considered to be supportive of a recovery process. Psychiatric medication and care was described by some as being too intrusive and fostered dependency when recovery requires **“taking responsibility for my own wellbeing,”** which **“reduces dependency and increases the odds of remaining well.”**

## Part of the solution, but not the only answer

The role of medication, whilst important, was only part of what most people needed to recover. It was required to be accompanied by other processes, which included working through issues, communicating with people, finding support in community environments, self help and self determination, and other non pharmaceutical treatments.

Several people shared their discomfort with taking medication, not only because of the side effects or dependency, but because they *think* they should not be on them. Negative attitudes towards medication resulted in people recognising their worth, but feeling bad or guilty about taking them.

**“I don’t like being on medication at all but, erm, if I have to be on it... a level of medication is better than no medication at all.”**

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**“I resisted for a long time but I’ve got to the point that I just take what I’m given and don’t let it worry me. If it does some good and is helpful then that’s okay?”**

## Trial and error

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Finding the right medication and dosage was said to be a matter of **“trial and error”** with prescribing clinicians over a long period of time. Narrators reported on their struggle through increasing symptoms, a range of side effects, and a lot of lost time to find the right balance of medication.

**“I reduced my medication about a month ago thinking that I’ve got rid of them (voices)... but within about five or six days I’d begin to get symptoms again... So I took 15mgs instead of 10mg when I got home and I was ok the next day. So I’ve learnt that I can’t go without my medication. It’s just finding the right dose. You can only do that by trial and error which I did.”**

For some, who have not yet found the right medication or dosage, the benefits of taking current medications were still thought to outweigh the side effects. Dealing with sleepiness, physical symptoms, reduced communication abilities, and even the loss of a driving licence was found to be preferable to living with the symptoms of the illness.

**“The neurologist wanted to muck about with my medication because the tremors could most probably be coming from (drug name) and lithium because they can both cause slight hand tremors, and if they’re together it can be worse. Some days it’s alright and some days it’s really bad, and I really dinnae want my medications mucked about with.”**

## Medication problems

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Over a third of narrators felt that the medications and their side effects had actually hindered their recovery. Years of changing medications and coping with the consequences often made people feel worse and potentially set back recovery journeys. For some, the side effects experienced were considered to be worse than the illness, affecting their physical health, and making them tired, de-motivated, and confused about what was happening to them (particularly if not warned about the side effects in advance).

**“I got all the literature and I had a list of all the anti-depressants and anti-psychotics and so I took one (drug name) and looked it up on the form and I thought ‘God almighty! The side effects are worse than the cure!’ and I threw them down the toilet.”**

People were also concerned about the longer term impacts of such medications, addictions and the difficulty associated with coming off them.

**“It scares me that somebody might want me to try coming off my medication, I’m no sure what’s going to happen to me when that happens... But I’ve been on and off anti-depressants since the age of (AGE) and now and then you’d start to feel better and a doctor would come along and say ‘well you’re doing fine now’ and take you off your tablets and within three or four months you’re right back to where you started... I don’t think it’s a case of if it happens, I think it’s when in my experience.”**

Most individuals felt that they did not have enough information about the medication they were asked to take. Some people refused to take them if they did not agree with the diagnosis, had a bad reaction to them, or had heard something bad about them. For one narrator, this resulted in being sectioned and being forced to take medication.

**“So I decided then that I didn’t want to take their medication anymore, because that wasn’t working. I’d tried that for a while, and it wasn’t working, so then they just sectioned me instead, and forcefully gave me the medication... You need to fight for your rights... to make people realise that you’re a human being, you’re not just a set of symptoms... It was that combination of things that gave me the confidence to be able to say ‘No, I don’t agree with what you’re saying to me.’”**

A lot of individuals felt that they were at the whim of their psychiatrist whom they felt often knew little about them as people, with each new psychiatrist prescribing a different drug or removing drug treatments and setting people back when the new drug was not effective or relapse occurred. This sometimes caused a loss of faith in prescribing clinicians.

There was a shared feeling that most doctors focused too much upon medication. Narrators also questioned the advice they were given; that they would have to be on drugs for life. Doctors were said to keep increasing dosage, adding to and changing medications when the first prescription didn’t work which resulted in people being resentful about being over medicated.

**“You know, clinicians tell you ‘oh yes, you need medication forever, you need to do this forever, you need to do that forever’, but that’s not true. And if you don’t take a chance you’ll never know.”**

It was felt that medication is often the easy answer when someone is psychotic, but given time and resources, skilled people can talk you down, medication alone is not enough to help individuals recover. Despite recognising advances in drug therapies over the last 20 years, several narrators stated that talking therapies, establishing support systems and stability were a more effective way forward.

**“Well it’s been a very long process and I think it will always be there so initially it was the talking that helped me, with the psychiatrist, that definitely helped... that helped me feel that I wasn’t so isolated and there were lots of other people from all walks of life that had had problems and that helped me think I wasn’t so alone.”**

**“So really medication doesn’t actually help. In some cases it’s actually talking therapies that we need, it’s psychotherapy and that’s one way to recovery.”**

Medication was not only difficult to get right, it was also considered to be creating a false sense of recovery. It was seen as a response which *“focus(ed) on symptom control and symptom suppression”* rather than a tool for recovery. Individuals describe it as addressing symptoms not causes, and as something that stops you reaching your potential as a person.

**(Medication)... “It’s not about making you a fully functioning member of society, it’s about making you compliant, and you won’t do the bizarre things in the street, you won’t be threatening, you won’t appear anything apart from normal. The fact that your feet are stuck to the floor and you’re bright yellow because you’re jaundiced because of the medication is beside the point... You may be thirty odd years old, but you look like you’re ninety... You can’t walk, you can’t talk, you can’t do anything, but the symptoms of your mental health problem aren’t there to**

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**bother anyone... You know this is my life! It's all right for you to come into my life and tell me 'oh, you need to get a grip, just take your tablets you'll be fine'. You know that's not recovery! That's about keeping, maintaining me in the community."**

There were those people for whom medication just did not work, or worked for short periods and then became redundant. Some felt better without them so disregarded them, others decided ***"I don't want to compound my difficulty by becoming reliant on medication."*** In each of these cases individuals developed alternative strategies to manage their illness and their recovery.

**"I don't feel as if the medication was the big thing that helped. I feel that it was all the hard work that I did, but the medication must have been doing something, it must have done its job as well. And I always took it until I was told not to."**

Some people had not taken medication for more than ten years without significant relapses into mental ill health. For these individuals and for others, recovery is most associated with the reduction or cessation of medication over time. However, they acknowledge that medication has a role to play en route and can be quite difficult to stop.

Most narrators indicated that they would ideally like to live with minimal (or no) medication.

## Hospitalisation

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Findings from this chapter reflect numerous experiences of hospitalisation and service use. However, we did not always know how recent people's experiences of these services were and recognise that practice may have improved over time.

Hospital was the right place to be when *very* ill. With hindsight many of those sharing their stories recognised that when they were very unwell hospital was probably a good place for them.

**"What does it say about society that somebody actually feels more secure and comfortable in a hospital that is far from perfect, but they actually feel more comfortable there."**

A sense of relief at being cared for, getting a diagnosis and accessing the services they needed was described, although the experience was described as being awful but necessary. Several narrators acknowledged their determination to 'get out' and not return as the catalyst or turning point in their recovery.

A range of problems with admission to hospital were identified. These included being forcibly detained, over medicated and under stimulated. People also identified a lack of one on one support and counselling on wards.

**"I felt the staff on the ward were just there to assess me and give me medication when I didn't want it really; I just wanted somebody to talk to about something – and I didn't find them at all supportive."**

**"People would rather be in their own homes because they go into hospital and they deteriorate in hospital because there's not care in hospitals except for medication."**

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## A sense of security

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Hospital was also described as a refuge, a place where individuals could escape from their problems, marriage breakdowns, homelessness and generally not being able to cope, a place where they could be left alone. However, narrators also noted the hospitals' focus on treatment rather than recovery strategies meant that they could end up in a cycle of re-admissions. This severely disrupted their relationship with their friends, family and support networks, disorientated them and created dependency, making it harder for them to recover.

**“That when I first went in... I felt safe, and I didn't want to go anywhere else, I just wanted to be there. I kind of felt cocooned. Not that people understood me I don't think, but I didn't feel that I was in any sort of danger.”**

**“So often, actually being admitted to hospital and hospitalisation and dependency actually add to the issues rather than actually solve them.”**

For some narrators, hospitalisation was more than a refuge, it was a place where they found that they did not need to put on a front and could access activities, relaxation and visualisation techniques that could help launch, or re-engage with, their recovery journey. It was felt that this could be improved by establishing effective links between hospital services and support services in the community.

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## Peer support in hospital

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Some people found strength in the communal nature of hospital wards making hospital more of a part of their recovery experience. The value of empathetic and informed peer support provided between patients was also recognised.

**“The experience of being in hospital in the ward environment, a communal environment about being together – you're almost there for no reason except to get well. It's a fantastic environment. You hate going in there at first but when you get used to it, it's idyllic in some ways. There's lots of support.”**

**“The most help I got was from the other people in the ward who had gone through similar experiences. And this does generally go on when you are sectioned. The nurses, they're great but you find, or I find – you asked for my personal experience – the best people that helped me were other people that had been through psychosis, had some little pointers, were grounded, that's the thing.”**

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## Problems with hospitalisation

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Hospitalisation potentially hindered recovery through arousing fears, promoting power relationships between professionals and service users and through enforcing control and a maintenance paradigm. Narrators reported being frightened and shocked by the process of admission, the environment and the way they were treated.

Several people related their shock at the time of being sectioned under the Mental Health Act. In the main, this shock related to feeling uninformed, not knowing what was happening and feeling that 'nobody had the right to do that to me.'

**“I hated it. The first night there I was not even introduced to the night staff, I was made to queue up with everybody else in the hallway for my medication and to have a staff nurse turn to his nursing assistant and say 'Who's this?' Not even introduce themselves.”**

The reputation and physical appearance of some hospitals did little to comfort or reassure individuals. Indeed, one individual described their local hospital as *“Dracula’s castle,”* a prison, a building where *“there’s razor wire all round.”*

The mix of people in wards was highlighted as a problem. Women felt uncomfortable about being in mixed wards with men when they felt vulnerable. Concerns were expressed about being on wards with seriously ill and potentially violent people. However the main concern was that being locked up with *very ill* people was impeding people’s recovery.

**“I says, ‘I pray and hope that I have never ever to go back to hospital again’... there are mixed wards, men and women mingling together, and when you are ill and vulnerable you don’t want to wake up and see a man brazing up and down the same place as you are, and it’s horrible, and I have had this argument a lot of times, I don’t like this mixed wards in a hospital.”**

Narrators describe being infantilised, disempowered, treated as if they were dangerous, left uninformed about what was happening and being labelled as an illness not a person. This dehumanisation and lack of understanding of their needs added to people’s poor mental state. This compounded by a lack of freedom, being in locked wards and not going out for weeks was deemed unhelpful and made people *“irritable and aggressive.”*

The reduction or removal of control and choice over space, movement, privacy, money, food, medications, treatment and duration of stay left people feeling disempowered and undermined.

**“Ok, you’re a voluntary patient, technically you can sign yourself out, but you really don’t want to... I was told nicely that I could do that but then I would be getting a visit and I would just be sectioned and straight back up.”**

**“I says ‘I am not a little school-girl to be told you will’. And this is something in (HOSPITAL), you have to line up for your dinner, you have to line up for your medication, which I don’t think is right.”**

Several respondents found convincing professionals of their readiness to leave the hospital environment was difficult. A small number of narrators felt that professionals needed to be less risk averse and to allow individuals to care for themselves when they are indicating that they want to be independent. On the other hand, when individuals were on their way to independence, professionals needed to be more supportive and to offer reassurance that problems faced are not insurmountable.

**“At that level where you really wanted to get out and you knew there was a way somehow but you couldn’t quite find it. Or you seemed to find it and then your specialist would say, ‘no you haven’t found it, you know. We think you should be in for a bit longer. No, no, we’ll extend your weekend pass but that’s all’... and I don’t want to be in here.”**

Whilst narrators recognised that hospitalisation can offer opportunities for recovery, what they have shown is that in practice, much needs to be challenged for recovery to be better realised. During hospitalisation attention to the individual, their sense of self and worth was considered very important. It was felt that a focus on maintaining the rights and dignity of the individual throughout their stay would build on the sense of security and care people experienced and add an element of empowerment as a resource for recovery.

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## Talking Therapies, Counselling and Psychotherapy

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Talking therapies were experienced as particularly helpful and were said to be a primary route to recovery. Already identified as an important recovery strategy by our narrators, they used them to deal with long term issues and to reframe the way they see and feel about things. This type of therapeutic interaction was often expressed as being enjoyable, and resulted in an increased sense of wellbeing that enabled people to re-engage with work and other life situations.

Talking therapies were experienced most favourably when they were supported with other medications.

**“Talking therapies are no good without my medication, I need both. Helping people understand that what might suit one person might not suit another, and, uhm, a bit of everything.”**

**“I got a psychologist for the first time, and started cognitive behavioural therapy; CBT. And the combination of that and the day support and the individual support I got from a voluntary sector organisation. I think that’s what did it.”**

Some articulated the need to extend psychological services to ensure a more holistic approach within the mental health system.

**“There isn’t enough consideration of the person holistically, there isn’t enough consideration of alternative therapies, there isn’t enough consideration that, if people had quicker access to talking and psychological therapies perhaps their reliance on pharmaceuticals could be diminished.”**

The impact of the different types of talking therapies depended most strongly on the extent to which the approach was person-driven (focus of therapeutic process, timing, duration and location) and the rapport with the therapist.

Psychologists who provided people with the opportunity to talk things through, think differently, break through bad feelings and cycles, understand their strengths, see things rationally again and develop the confidence they needed to address issues were found to be instrumental in a number of narrators journeys towards wellbeing. Narrators regarded this way of working, where they got feedback on progress as very supportive and also appreciated that, once accessed, psychological services tended to be more available than other services when you were going through *“a low patch.”*

**(Relationship with Psychologist) “It’s been a very important relationship for me. It’s changed my life.”**

Psychotherapy provided people with techniques to move forward, to manage other problems (such as alcoholism) and get back on track quickly and effectively following minor relapses. It was noted that entering the process in a good frame of mind and developing a good relationship with the therapist facilitated its effectiveness. Success was almost without exception dependent on the narrator expressing that they had a good relationship with the therapist.

Having experienced psychotherapy people often wished professionals had suggested psychotherapy sooner and reported that it was the only thing that helped.

**“I think psychotherapy is the only thing that could help me.”**

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**“I think the things that helped this last while, was getting psychotherapy you know it really helped things out.”**

One narrator who paid for a year of psychotherapy reported that it **“*didn’t help me at all. I felt worse at the end.*”** However, it was recognised that the value base of therapists is more important than their particular methods.

Several narrators found regular counselling over time with the same counsellor to be a useful support to their recovery. It has linked them to internal and external resources that have helped them face issues and better understand why things have happened in their lives. Counselling also helped people to deal with daily anxieties and to make changes for the better. In situations where counselling had been successful, narrators often reported a reduced need for it over time, until it was used rarely – on demand. However, person-centred counselling was found to be particularly useful to some individuals *because* they had developed a longer term client relationship and saw no need to reduce or eliminate counselling from their treatment schedules.

**“I suppose it’s the talking therapy, the counselling and the talking therapy that have been the most useful.”**

**“They started me with counselling. And that was a great place to start because I started realising why things had happened in my life and what way I coped with them, what way I didn’t cope with them and what I was prepared to put up with, what I was not prepared to put up with and how I was going to sort of fit in with my family, things like that. We sort of explored issues from the past and the present and that’s where I started to think.”**

Narrators most often accessed counsellors and therapists through their GPs.

## Group Therapy

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Opinions were split on the efficacy of group therapy. Those that were in favour of it often found one to one counselling too intense and appreciated the peer support offered by groups. They felt there was value in working through issues with people in similar positions – it was easier to have their behaviour commented on by their peers than by professionals. Listening to the advice given to others helped them make more sense of their own situations. They also found that other people could offer insight into their lives through reflecting upon their own experiences.

Whilst several narrators found group counselling **“*intense*”** but unhelpful, a non-heterosexual narrator reported such environments to be difficult due to the assumed heterosexuality of the group and the homophobia of some group members. Where prejudice was apparent in these groups the experience of it appeared to be intensified as individuals could be made to feel like ‘an outsider’ very easily.

Some people had been involved with group therapy as an alternative to one-on-one counselling. Some established group therapy support groups explored alternative therapies such as massage therapy and aromatherapy. Engaging with these types of services was found to be very positive, encouraging socialisation and sharing of coping strategies for recovery in a setting where clear contracts about self-exploration, professional and personal boundaries exist.

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## Cognitive Behavioural Therapy

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We often heard that CBT helped individuals deal with anxiety and managing voices, and helped them to recognise when they were becoming ill. It taught them how to think and react differently and move away from behaviour patterns that could maintain them in illness.

**“I went through a lot of therapy, cognitive therapy, behavioural therapy... While I was being taught it I wasn’t actually able to put it into practise because I was at too low a level, and it’s only in the last couple of years when I have been thinking about where I was going and what I’m doing, that I can actually use those skills, now, to help me to be where I am. So... in hindsight it has been very, very useful.”**

**“I have found personally that cognitive behavioural therapy is what’s worked for me. It doesn’t work for everyone... it’s hard work and it takes a long time! Um, but it gives you that sense of ownership over yourself again, I think that’s what you need, because I agree that the principles of recovery are that you live well, and you live with your symptoms.”**

Whilst many people found CBT useful, others were wary of it. As with other treatments and supports people noted that finding the right person *for them* was central to success or failure. For one person finding a therapist that would acknowledge and talk to their voices was instrumental in making CBT successful.

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## Other therapeutic interventions

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Occupational Therapists were recognised as helpful. They encouraged individuals to focus on wellness and facilitated them to get out and about. They encouraged people to use hobbies such as gardening, carpentry and photography as part of their recovery strategy after leaving hospital, recognising that such activities also help to alleviate symptoms to a certain extent.

A range of alternative approaches to managing their mental state, reducing anxiety, anger and stress and increasing resourceful states were explored by narrators. These range from hypnotherapy, anxiety management, motivation and anger management techniques, anger management courses, relaxation techniques, music therapy, art as therapy, life mapping, re-birthing, bereavement counselling and CBT. Individuals found such approaches useful in providing strategies and techniques to limit stressful states, however some of these processes were quite demanding emotionally.

**“When I did my music therapy I can remember saying my life was a whole jigsaw and it was all broke into thousands of pieces and that I wanted to make a picture on the other side with all the pieces but a different picture and it’s putting those pieces together that is very difficult so for the future, just keep putting the pieces in the jigsaw... and being accepted for what I am.”**

A very small number of narrators shared their experiences of therapeutic communities in Scotland and found the opportunity of seeing peers modelling recovery in these communities very useful.

**“(talking of group therapy in therapeutic community) Everybody’s in it together, erm, that it’s your peers that are commenting on you instead of someone qualified who is almost sitting in judgement – it is people who are going through the same things that you have gone through.”**

Individuals describe a strong sense of belonging when living in such communities and that it feels like being in a family where you have the opportunity to learn from each other. The social aspect of community living provided people with a ready social life that was felt to enhance the recovery process. However, narrators also acknowledged that the intimacy of the community experience made it difficult to leave. Individuals describe leaving on a high that sustained them initially but then having to develop strategies to deal with the short term lows experienced as they re-engaged with their lives outside.

**“It has been a difficult journey since I came out. When you leave a therapeutic community like that I think most people come out on a real high which lasts for a long time... and that tremendous feeling that you have achieved something, and then gradually that very high has faded away to a level probably a more realistic level.”**

## Alternative/complementary medications and treatments

Relatively few people discussed having explored other non-prescribed medications. One person had used Saint John's Wort which reportedly interfered with other medication. More individuals were happy to try complementary therapies. These included aromatherapy, magnetic re-alignment, crystal healing (and others). A few narrators firmly believed that alternative therapies worked more effectively than mainstream ones.

**“In terms of the traditional statutory services, it's like anything else, uhm, it's very much dominated by the medical model. There isn't enough consideration of the person holistically, there isn't enough consideration of alternative therapies, there isn't enough consideration that, if people had quicker access to talking and psychological therapies perhaps their reliance on pharmaceuticals could be diminished.”**

Others were happy to combine the positive elements of mainstream and alternative therapies.

Complementary and alternative therapies and approaches have been an element of people's recovery but the cost of participation in these therapies where they are not provided by the NHS was found to be prohibitive.

## Psychiatrists

Psychiatrists were a significant feature in many narrators' recovery journeys. Once trust was established, they helped people to sort out issues and were seen as a resource to the recovery process whether seen regularly for years or on occasion as required.

**“My psychiatrist said the that fact that people don't get better it means that something is maintaining their illness. He thinks you know to some extent and again he believed in the healing process if something is not healing then there must be something else at play there.”**

## Relationships, attitudes and power

Many people described how they wanted psychiatrists, to take a more holistic view of them. Although they did want them to explore their symptoms, they required to be seen as more

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than a set of symptoms. People perceived a lack of empathy and understanding of their history and the circumstances related to their ill health and life situation.

**“Psychiatrists most of the time came across as being cold and unapproachable.”**

**“If psychiatrists were a little more understanding... If they were just taking maybe a little more time to understand what people’s feelings are, there wouldn’t be so many patients.”**

Problems were seen to be, in part, due to the limited time spent with professionals. Consultations were said to be too short, not as often as required and inconsistent. The power differential between service users and psychiatrists, who were described by some as distant, intimidating and authoritarian, was also discussed as a problem.

**“From that first psychiatrist that I saw... I found (them) quite distant.. and that was quite intimidating,.. because they’re keeping me at a distance.”**

**“They got me to see a psychiatrist. I think I was, I was quite intimidated... you know..., authority figures... So I was quite... afraid of this person... and she started asking all these kind of questions... which was very, very difficult because it makes you feel quite exposed... especially if you’re trying to hide. So I had a lot of kind of inner conflict and... to trust somebody that you’re afraid of, you don’t know anything about, and when you’re sitting there – you’ve had a nervous breakdown – and you’re thinking ‘God, I’m absolutely barking, I’ve lost the plot, you know, like you sort of feel... what am I capable of doing? If I come out with such and such – if I actually tell this person what’s going through my head, are they going to lock me up and throw away the key?’”**

People expressed that negative assumptions and judgements being made about them, based on limited information, had prevented them getting the right diagnosis and support, and therefore hindered their recovery. Fear of psychiatrists’ power to incarcerate, make judgements, disbelieve and dismiss people’s experience made them feel particularly vulnerable. The very professionals they needed to turn to for help were the same people that could have them forcibly admitted to hospital.

**“I was scared, I had enough if you like insight to realise that if this psychiatrist sees me and I tell him that I think I’m Jesus I could be locked away for life.”**

Having a good relationship with your psychiatrist was a turning point for several narrators. Where psychiatrists had good rapport, openly communicated in non-complex language and informed service users about their illness in a hopeful way, it gave individuals a chance to be optimistic about their recovery potential. Letting people talk things through, being committed to them and showing empathy for their concerns helped several narrators find their recovery feet.

**“(What’s helped) A good psychiatrist for a start. When I left hospital for the first time I didn’t want to get him because I thought he was some kind of authority figure, but I came round after a couple of years and I have had him for eight years or something he kind of keeps me straight. I see him every two months.”**

**“Well it’s been a very long process and I think it will always be there so initially it was the talking that helped me, with the psychiatrist, that definitely helped.”**

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## Housing and community supports

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Having a supportive environment, somewhere to call ‘home’ was reported as important for stability and safety and provides a base for contact and support from friends and family. Housing problems or the lack of a supportive ‘home’ environment, was found to adversely affect recovery potential if not addressed.

Narrators passed through various types of accommodation on their journeys to wellness, indeed the numerous types of accommodation experienced by narrators adds emphasis to the highly individualised and dynamic nature of recovery journeys. Throughout the various types of accommodation they inhabited narrators were united in their view that affordable and comfortable accommodation that provides security, stability and shelter within a supportive community is necessary to facilitate their recovery journey.

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## Housing Finances

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Housing benefit and other forms of income maintenance has enabled narrators to keep their mortgages and maintain rented tenancies, however, confusion over entitlement and fear of losing benefit often forced individuals to stay in unsuitable accommodation. The rules governing these benefits also proved too stringent for some narrators who feared losing their benefits and associated accommodation after lengthy stays in hospital.

**“I can’t change my mortgage while I am on benefits and be assured of getting the same support. So I am stuck where I am at the moment until I can get back to work.”**

**“The minute you tell them of any changes, like that with the housing and somebody had reported me and they stopped the housing benefit without actually checking it out, they stop it and then they check it out.”**

**“The housing fraud people came to visit. I was thinking that I was going to lose my house because I am not living in it. So my house, if I stay away from more than two years, I lose my house, so it doesnae do anything to help your recovery.”**

Some narrators found that being on benefits limited their ability to choose accommodation whether it be rented or privately owned as they were unsure if current benefits would transfer to cover the costs of new property.

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## Own Home

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Having your own home was found to increase subjective wellbeing. Some narrators indicated that having something to own and look after, a private space in which to develop and recover, gave them a sense of self-respect and pride. This helped them to move from being ‘that person with mental health problems’ to being just another respected member of the community.

**“When I got the flat that I am in now, for the first time it was my house and it was my space and I could fill it with my memories and, you know, there wasn’t any baggage there... and it was a place where nobody knew me, nobody knew that I had mental health problems, nobody knew who I was. I was just a person who had moved into this flat, and it’s still the same to some extent, you know. I’ve got the kind of privacy that, you know, that people, well people know, obviously when coming out of the house, they see me in the lift, but it’s not like ‘here is this person with mental health problems living in this house.’”**

Having physical space was important for individuals. Some people liked to share the space with others whilst others valued solitude and their own space. Narrators emphasised that this choice should be down to the individual. For some of the people that had been hospitalised the idea of living on their own was daunting, whilst some became accustomed to it over time before growing to like it, others felt a sense of isolation and lack of support.

Feeling rooted and stable in their homes increased people's confidence. One narrator believed having your own home puts you on a more equal footing with professionals that visit. Indeed, for some, even contemplating owning property and taking responsibility for it was in itself evidence of recovery.

**“So now as long as I keep working and pay my rent I have my house and it's all mine. I need the security.”**

**“Having my own flat removed most of the power-balance along with a few professionals who rose above their professional barriers and treated me as an equal and supported me through my choices and testing of myself.”**

**“I'd love to have a little house somewhere very modest that is mine you know just to be allowed to live my life in peace.”**

## From hospital to community

Most issues that concerned housing in narrators' stories related to the transition from hospital to community. This transition was regularly smoothed by housing support agencies with varying degrees of success. Having the right and responsibility to look after yourself after a period of institutionalisation helped individuals grow in many ways. Indeed, some narrators fulfilled lifetime ambitions upon gaining their own home after hospitalisation, and many individuals equated moving into their own accommodation with improving their sense of self-esteem. However, many individuals faced numerous accommodations and tenancies before finding settlement and security in their home.

Some individuals in more rural or island settings reported problems in transition from hospital back into the community indicating that resettlement accommodation was often located in isolated areas that were not well serviced by support networks. A small number of other narrators also indicated that the housing offered in the community was often in less preferred locations, forcing 'first offer' houses to be rejected.

**“Some of our members have had major problems when they've come out of, of the acute psychiatric unit and maybe lost their homes because of their illness. They are getting housed, out, way out in the country, the other side of (PLACE).”**

Moving back into the community from the safe, social and nurturing environment of a hospital was a big step and required delicate help. Transition from hospital to the community needed to include time to recover from being *in* the mental health system.

**“You are put back into the community you know, and it takes you a bit of time to get together and that, and how you feel... I think a bit of understanding sometimes with people and that, you know you can't just get through on fresh air, but I think it's a bit hard for people to change, to change from what I was like in a sense, to fit back into the community, from being ill. It's hard like.”**

Phased transition to living at home posed some very practical challenges. Some hospitals

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provided link services to patients, trying to help them regain their independence at home. These services were appreciated by narrators who were learning to cope for themselves again.

**“Some of the nursing staff would come over with me in the car and look at things, which again were every helpful and great, and that was good... they did link you back to home, I couldn’t criticise them for that, if I wanted to go then someone would come with me in the car.”**

Services such as link services, supported accommodation or housing support helped ease the initial loneliness and difficulties of moving back into or being isolated in a community.

**“...’Cos for a lot of people it is incredibly lonely when you come off the ward, surrounded by people, to your house, where the only person who lives there is yourself... like a half way house, it’s making that transition, because being in hospital is one thing and being at home is completely different.”**

Some narrators found it difficult to reintegrate into their community after being given their own accommodation. They felt the reduction in support to be challenging and in some instances felt incapable of leaving their house; overwhelmed by the numerous things that householders have to deal with like paying bills, maintaining a house, keeping appointments and socialising on top of looking after themselves. An apparent service gap was evident in these circumstances.

**“They are closing all the hospitals but they are not actually putting trained workers in place to deal with the people coming out of hospital.”**

Overall, this transition process needed to be done at your own pace. Taking on too much too soon was not conducive to good health.

**“I would definitely like to see more support in the time from when you’ve been going all the time and getting it everyday to when you come back and then you’ve got somebody once a month.”**

## Maintaining a link with home

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Where narrators were supported to maintain links to their homes whilst in hospital, transition back into the community was much easier. Being encouraged and supported by staff to go back and check their homes, feed their animals and meet their friends at home, and to gradually increase the frequency of this over time eased the return to community. However this gradual reintroduction often created its own domestic problems, especially where people lived part time in both environments.

**“The problem was having to get just enough stuff in the house, just last those three days. Instead of doing a weekly shop, you couldn’t, could only plan it for three days because if you had any more than that, heck if you didn’t come back again it would go off in your fridge and smell.”**

Regardless of phased reintroduction programmes, some individuals still felt that their reintroduction to the community was very fast, and appreciated being able to keep up their links with hospital led activities. The practical help and emotional support provided by CPNs to people returning to the community from hospitals and therapeutic communities was well received.

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## Supported Accommodation

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Many narrators had lived in supported accommodation at one point. Some compared it very favourably to being in hospital.

**“In a way it’s like having the best of both worlds because you’ve got all the home comforts and everything and at the same time if you don’t feel well there’s always someone on the end of the phone to talk to, so yeah it’s the best of both worlds I think.”**

The freedom that supported accommodation affords combined with support allowed individuals to share responsibility for self and others and allowed them to gradually make choices and become more self-determined. It allowed individuals to develop their individual identity offering more freedom than hospital and support as people re-engaged socially finding their place in the local community.

Shared domestic responsibilities and communal living with people who had similar issues allowed for the development of people and life skills in a safe space and built confidence, self-sufficiency and caring skills.

**“It was such a large house, you were sharing with about eighteen people including the staff and the house would tend to get quite dirty and people would leave cups and things all over the place. So in the morning you had a cleaning sort of two hours where you would clean the house and then some people would go out and get shopping for the day as you were going to feed people... In the evenings you’d get involved in cooking, so you would end up cooking for about eighteen people which was quite fun.”**

It was noted that as ‘people living in the community’, individuals were better informed of the range of supports available to them than they were in hospital. Supported housing provided more stability for people in transition from hospital than did the temporary accommodation that a few narrators found themselves in. The stresses associated with temporary accommodation reduced the energy and focus on keeping well, although for one narrator this served to hasten their recovery as they made the effort to move on.

The negative aspects of supported accommodation related to feelings of loss of power and not being at home, and to feeling like a guest in someone else’s home.

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## Housing Support

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Housing support services offered to find accommodation suitable to individuals’ needs – usually via housing associations or local authorities, they also aided individuals’ resettlement in their own home. They assisted individuals with benefit advice, managing finances and documentation, and finding out about local community facilities and services.

**“I think that the support I’ve had from the housing support organisation has been a key factor (in recovery). I was introduced to them a good number of years ago, and I’ve only ever been shown respect, and treated as an equal. I think that recovery has allowed me to take on that responsibility and live independently in a flat, with support from (AGENCY), and that in itself has given has given quality of life that I’ve never experienced before.”**

A few narrators felt that their recovery journeys had been set back by having inadequate support in their homes after release from hospital.

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**“I didn’t get the help that I needed and the type of help I needed at that time, whereas if the support had been there, in the way of housing support and things like that, I could have then gone on, I believe, to recover far sooner.”**

People expressed the need to be in control of the support they were given. The security of knowing that someone could come to your house to provide help should it be required was a very important safety net for individuals as they increased their level of independent living. Even if they seldom needed the support, just knowing it was available was often enough. It was felt that it was important that such support was not forced upon individuals and that they should have a say in the whom, when and how it is delivered.

## Homelessness

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Insecurity of housing tenure and homelessness intermittently hindered recovery for several narrators. To be faced with the prospect of homelessness was considered to be damaging to individuals’ sense of self-confidence and recovery potential.

**“Well, I was in one hostel; it was just a homeless hostel. It wasn’t beneficial, it was good to be around people, but it didn’t help me address myself or my symptoms.”**

**“I was homeless they wanted me to move into a hostel and immediately, and I always owned my own house. I couldn’t, it was the fear factor again, all these men they could be drug addicts or worse or God knows what so that’s sent me over the edge.”**

Homelessness was the result of a variety of factors including an inability to cope with bills, financial difficulties, voluntary or coerced removal from housing due to stigma, housing lost during institutional care or as a result of family breakdown. Whilst many of these reasons for homelessness can affect anybody, of particular concern to individuals with mental health problems is the prospect of losing a family home during extended periods of institutionalisation or being forced to leave a home due to perceived stigma in the community.

The financial implications of hostel living and homelessness are very challenging. Due to the temporary nature of many of these accommodations and the transient situation of the residents, time there was often accompanied by a lack of income. This further hindered recovery.

**“I think it’s quite difficult if you’re staying in a hostel environment, you only have a food allowance and a personal allowance to live a fulfilling life. How do you have a social life on top of that? Financially, it’s very difficult to do.”**

Narrators have shown that recovery is a dynamic and highly individualised process throughout which people develop self-determination and responsibility by developing coping mechanisms that allow the maturation of a sense of identity outside the illness. This recovery is aided by the sense of security and community one can feel when settled into a safe ‘homely’ environment and as such, support to obtain this environment should precipitate recovery.

## Financial security

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Having the knowledge that finances were relatively secure was one less thing to worry about for individuals. Financial security came from income benefits, wages from work, and from partnership incomes in a traditional domestic setting (housewife/househusband type roles) and from inheritance. It was felt by many that to be ill had costly repercussions in terms of lost

income and lost potential for earning greater income. For some erratic spending patterns at times of ill-health could contribute to the financial cost of ill health.

Although income maintenance benefits such as Disability Living Allowance, Severe Disablement Allowance, and Short and Long Term Incapacity Benefit and Tax Credits were found to be essential supports for those who couldn't work (or were on low income) questions of eligibility, entitlement, fear of withdrawal, difficulty in initially accessing the benefit and the low level at which several benefits are paid were factors that recipients found to be challenging and unsupportive to recovery.

## Independent income

Some of our narrators were financially independent and used income sources from paid employment, savings or inheritance to finance their everyday activities. For those individuals who were financially secure it gave peace of mind and was definitely appreciated as 'one less thing to worry about.' Whilst some participants were discretely guarded when discussing issues of a financial nature others were more forthright in their discussion.

**"I don't work at the moment but I had enough money that I didn't have to worry, which was fine. I mean I do know that I was spendy, really spendy but that's fine, I haven't left myself in debt or anything which is good."**

**"I don't have immediate financial problems. That's something that I am very grateful for. Though although I am kind of concerned about (finances) –, and I might say if I had absolutely no worry about finance that might be a help."**

Whilst some individuals had independent means, most received some form of income assistance from the state and in the main narrators' discussions around income focused on issues of benefits and supports and their role in recovery.

**"Well I get benefits obviously but the social security know how much I've got in my building society now and I'm sort of over the limit so that means they have to reduce the benefits... But no, money's not really been a problem over the past few years. I think as long as I've had money to buy fags!"**

## Income from work

Obtaining financial security through employment was an important aspect of a number of individuals' recovery journeys. Earning a living gave several narrators a high degree of pride and a sense of accomplishment especially where individuals had previously been benefit recipients.

**"Actually becoming a member of community and contributing to society instead of living off the state."**

**"At least I had done it and that made me feel good, that at least for three or four month I had actually held down a job and I had actually got paid. And that made me feel good that I wasn't, you know, totally living off benefits and I was, you know, I was going out to work and I was, you know, contributing something"**

**"Yea, and so from that point of view I am not willing to sit back and just be on benefits, I hate being answerable to somebody giving me money, you know, but, other than working for it."**

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There was a distinct financial imperative to work and access earnings in spite of ill health. Indeed, getting your life together equated to moving off benefits and into paid employment for several narrators. However, poor finances sometimes forced individuals back to work too early, also, some narrators complained of being forced to accept lesser rank positions in work after a period of absence due to ill health.

**“I know that when I went back to work the last time I was depressed, I had a job to go back to, that I didn’t feel I was ready to go back to work and one of the reasons that was quite nagging at the time was that my pay was going down to half pay and I couldn’t afford to pay the mortgage.”**

**“Aye. I was on £15,000 a year five years ago and I’m on £9,000 a year now. It’s still... there is people power... I’m not sitting here pleading poverty but what I’m trying to say is it’s trying to manage a different amount of money.”**

The pride that is found in the ability to financially provide for yourself and your family was often removed by ill health and welfare dependency. There was a general feeling that narrators didn’t want to be in a financially dependent position but that ill health and an inability to work had forced many into this situation.

**“It was difficult at the start because I didn’t have any way of communicating to authority and money was short so I just struggled on... I didn’t have the worry of a mortgage and Council Tax. That all was taken care of by the DSS. I felt guilty at first taking money, a lot of money, that I hadn’t earned but then it got through to me that I had to do this. But I didn’t like it; I didn’t like taking money from the government for not working.”**

For some individuals, having the burden of coping with family budgets removed or shared with partners aided their recovery journeys.

## Low income

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For some, a frugal and diligent attitude towards finances helped them maintain order in their money dealings and helped them evade the stress of financial worry.

**“I try and be more frugal with my money like, try to walk a lot... I don’t need to waste money... So I don’t have to worry too much about financial problems and I’ve got savings in the bank, and the fact that my partner’s not working can be a hindrance but he’s determined to look for a job and I think he’s smart enough and we don’t do dead expensive stuffs, activities I mean.”**

**“(Of being on benefit income) you learn to live on what you need rather than what you want, that’s for sure. And feel quite satisfied with what you need as opposed, I mean, I’ve never really been materialistic anyway but I actually feel guilty spending money on something that I don’t actually need nowadays.”**

For some who had a low income, financial insecurity became an enduring stress. Almost all individuals were of the view that consistent financial security is needed to promote recovery.

**“Finance is very important to me. If I’m in debt I get ill and don’t feel well but when I’ve got money in the bank I feel fine. It’s as simple as that. I don’t know why but there is some kind of correlation.”**

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Having a fixed or low income removed the opportunity for some individuals to plan their future with any degree of financial certainty and was therefore a hindrance to maintaining their recovery. Most of the narrators who were not in paid employment received several sources of benefit income to cover living and social expenses. The combination of these benefits plus in kind services was acknowledged as helping them pursue more fulfilling lives. For some it meant that they did not have to consider going back to full-time employment and could establish a more manageable lifestyle that included limited work, volunteering, education and creative activities.

## Income maintenance and dependence

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There is a fine line between empowering individuals with benefit income and creating dependence according to several of our narrators. Numerous individuals recognised that dependency on benefits is not conducive to their idea of recovery. They indicated that to become 'used to' being on benefits can be detrimental to self-esteem and the desire to contribute can be eroded by lack of motivation. For individuals accustomed to working, going onto income maintenance benefits were initially found to erode confidence.

**"I think a lot of people have got used to being on incapacity benefit and they don't have so much motivation to pull themselves out of it. And some people are difficult and manipulative and it's not good for me really, and there are others who do a tremendous amount of work for people and a lot of them are as badly off as the people who they are helping. So I found myself getting a bit pessimistic about that really."**

For some, being granted benefit income helped their recovery as it legitimised or confirmed their illness and acted as a focal point from which to recover. Benefit receipt provided many with financial autonomy which improved self-confidence and self-determination as well as easing more pressing money worries.

The overall feeling from narrators was that income maintenance supports take the pressure off financial worries and allow individuals to concentrate on trying to get well, pace their re-entry into work or other purposeful activity, lead a healthy creative life and maintain their social life.

**"Finances are something that can hinder and help recovery. The safety net of having comprehensive benefits... it does help your recovery, it keeps you stable while you're ill. You know but for a lot of people they get too comfortable whilst being on benefit and that can maintain their illness. Certainly I would recommend that people who are ill you know they don't have to have financial hardship while they are recovering you know."**

## Benefit problems

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Some individuals were caused undue stress when their means of financial support was removed by social security officers. The removal of time limited benefits often came at a period when individuals were too unwell to challenge this. Indeed, benefit removal served to temporarily impede several narrators' recovery journeys.

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**“I had just had, during a long period of affliction, I had only had Disability Living Allowance for twelve months, and then it was withdrawn. And I was just so hacked off, and I really couldn’t cope with the appealing against that decision, although I should’ve done at the time.”**

**“For two and a half years I had to appeal (for DLA) and obviously during that period of time I was on a very low income...”**

**“So I’m going through an appeal tribunal but the stress of that has made me unwell. I’ve had no support from my health care professionals because some of them have said they won’t provide evidence because they don’t have time to write letters - GPs and things. Others have said the best thing for my mental health would be would be having a job, employment and I agree if I was well enough to work it would maintain my mental health. And they think my motivations are financial and I want to sit on my butt at home and collect benefits and not go to work.”**

For one individual, the trauma of benefit removal proved to be instrumental in beginning their recovery journey. Their ambition had always been to support their family through work and the removal of benefit income forced this situation to a head. This triumph over adversity is further evidence of the diverse and contradictory nature of many recovery journeys.

## Navigating the benefits system

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Often when it came to applying for income maintenance, benefits agency staff and GPs were ill equipped to help individuals fill out complex forms. When people are ill they are not in a position to cope with the complex systems of assessment, information sharing or interaction required of them. Welfare rights officers, CPNs and support workers were often approached to aid form completion and to provide advice on the procedures, rights and implications for working and volunteering.

**“In 2004 I was quite unwell for the whole of the year, and I was so unwell that I couldn’t go through the stress of filling out a 16-page form to try and get the benefit.”**

**“The other week I went to find out what would be the implications if I worked more or less in my job – what would happen to the tax credits and that sort of thing.”**

One narrator commented that there are perverse incentives inherent within the benefit system to encourage folk to ‘stay ill’. The transient and often fluctuating nature of some mental health problems meant that individuals feared losing benefits when feeling slightly better. In return it was felt that this chronic fear didn’t help individuals get any better but merely added to anxiety causing some narrators to imply that the structure of the benefit system hinders recovery.

Trying to prove ill health in order to qualify for benefits was reported to be a rather undignified and often stressful experience. Proving you are ill has consequences on confidence and health as it exposes individuals to the more negative aspects of their mental health experience. Employers and social security officers often tested individuals to prove their eligibility for sick pay or additional disablement allowances. It was felt that this degrading and often undignified and stressful experience doesn’t encourage those in need to claim for the assistance they are entitled to.

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**“To be asked the same questions again and again; and the problem with part of this is the questions tend to be more of a kind of negative, incapable... it’s like... it’s almost like ‘prove to us how ill you are’. And that has an impact on your mental health.”**

It was speculated that the current income maintenance system in the UK is more geared towards helping people with physical illnesses and disabilities. Perceived problems with the current benefit system were that it is overly complex, difficult to negotiate, and depended on strangers (not your general practitioner) ‘believing you are ill’ at time of benefit application and interview.

**“Everyone with mental health problems always gets refused the first time they apply, and it’s all geared around physical problems – the questions they ask on the form doesn’t take into account mental health at all.”**

**“I think the benefits system should be changed to be more geared towards mental health people. And maybe through somebody who really knows you like your health visitor or nurse or the psychiatrist or somebody rather than a stranger who sees you for ten minutes and says, ‘Well you’ve driven yourself there, you know, therefore you’re alright.’”**

Overall benefit receipt was considered a positive experience, but application and a potential development of dependency on that benefit were considered negative experiences. Narrators implied that there is a fine line to balance between empowering individuals with benefit income or creating dependents.

For people with mental health problems the need to re-establish meaningful fulfilling lives is important. The personal, social and economic losses associated with mental ill health are often profound and require resources to recover a sense of positive future. The economic insecurity and stresses related to mental ill health can limit people’s sense of security and aspirations for the future. Although people can and do learn to live with, and take advantage of less money and more time, many narrators needed more clarity and continuity around their benefits and income support entitlements.

# Treatment and Supports Discussion

The recovery stories provided by our narrators describe a journey that is punctuated by occasional setbacks from negative experiences, stigma, loss of faith in self and others and a poor experience of support services. They are also punctuated by positive turning points like witnessing a peer's recovery, receiving a diagnosis or the right treatment, finding the right therapist, becoming financially secure, settling within a community and feeling a sense of belonging or finding love and acceptance in mutually respectful relationships. What is common in these stories is that individuals spring back in spite of adversity and learn from their experiences. Recovery is most definitely a non-linear and unique journey for individuals.

# Treatment and Supports Discussion

**The National Programme for Improving Mental Health and Wellbeing sets recovery within a public health context. The programme is working to improve the mental health and wellbeing of all people in Scotland regardless of their experience of mental health problems. One of the four key aims of the programme is to 'Promote and Support Recovery' (Scottish Executive, 2003b).**

As we have outlined in previous chapters, factors which may be described as internal to people in recovery, like identity and self direction, and the extent to which people are able to engage in meaningful activity are central to recovery. In addition, the way in which people who experience mental health problems are supported within their communities is vital. This reminds us that, in the main, people recover in communities and that we must be wary of assuming that the extent to which people recover is solely determined by treatments and supports offered. However, there are things we can do to consider the extent to which our treatments and supports are oriented around recovery. In doing so we must be prepared to look beyond traditional approaches and to be informed by the lived experience of people in recovery.

Scottish policy is conducive to promoting a recovery approach in treatments and supports. Many overarching policies and reports have explicitly or implicitly acknowledged or highlighted elements which we have been shown in this report to be important to recovery. The Kerr Report (2006) and Delivering for Health (Scottish Executive, 2006) recognise the need for people with long-term conditions to better manage their own health and wellbeing. The Social Work Review (Scotland. 21st Century Social Work Review, 2006) outlined the need to personalise social care services to ensure they meet individual need. The principles of Scotland's Mental Health Act (2003) link closely with many of the principles of recovery offering a supportive and rights-oriented basis for care and treatment at times of most severe illness, while importantly acknowledging the key role of meaningful activity. It puts duties upon Local Authorities and Health Boards to enable access to community supports, like employment and recreation. More explicit references to recovery as a framework for policy development in Scotland are to be found in Rights, Relationships and Recovery (NHS Scotland, 2006) and Delivering for Mental Health (Scottish Executive, 2006).

Rights, Relationships and Recovery articulates a new values base for mental health nursing and suggest that practitioners should adopt recovery *'as the model for mental health nursing care and intervention, particularly in supporting people with long-standing mental health problems.'* It outlines a number of supporting actions including the development of new recovery training for all mental health nurses which is being jointly progressed by NHS Education for Scotland and the Scottish Recovery Network.

The first two commitments of Delivering for Mental Health (Scottish Executive, 2006) relate explicitly to the orientation of practice and values and attitudes in mental health services in Scotland. Commitment one is to develop a tool *'to assess the degree to which organisations and programmes meet our expectations in respect of equality, social inclusion, recovery and rights.'* SRN have been working with partners to realise this commitment, adapting an existing tool 'ROPI' (Mancini & Finnerty, 2005) for use in Scotland. The Scottish Recovery Index (SRI) is being tested in a number of sites across Scotland and should be in general use by 2010.

The second commitment relates to the development of formalised peer support services, where people in recovery are trained and employed as a new type of worker to complement and add value to the existing workforce. Peer workers will be trained to use their own recovery

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experience to support recovery planning with service users offering the key elements of hope and self direction. This commitment to recovery-oriented peer support clearly recognises the unique strengths and attributes which can be gained through living with mental health problems and signals a willingness on the part of the Scottish Executive and stakeholder groups to be innovative.

## Diagnosis

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Receiving a diagnosis can have both pros and cons. For many narrators getting a diagnosis was reassuring and enabled them to affirm their own understanding of what was happening to them, confirm to themselves and others that they were not ‘making it up’ and allowed them to embark on their recovery journey. This journey included researching symptoms, treatments, medication and their side effects, learning from others and generally taking control of the situation. However, an equal number of people felt that getting a diagnosis disempowered them and opened them up to assumption and stigma, limiting their options in treatment, care, work, benefits and support in the development of recovery strategies. Diagnosis for most narrators continuously changed anyway.

The management of the process of arriving at and communicating a diagnosis and its implications for recovery need to be considered carefully and explored sensitively with people. People need to feel there is hope and need to be empowered not only to manage their symptoms but to take control of their situation. Systemic problems with assumptions around whether people can still work, access disability income benefits, need hospitalisation, care and support need to be addressed at time of diagnosis to ease fears.

The assumption that mental illness is a lifelong condition is reflected in the continuing hesitance of many mental health professionals to provide a positive prognosis for social recovery (if not full recovery) for individuals. Hamilton-Wilson *et al* (2005) argue that experienced clinicians often believe that diagnosis of a psychotic disorder means the end of a fruitful and meaningful life. Given narrators’ responses to diagnosis it is evident that this belief is still being transferred to service users with potentially damaging long term consequences.

## Continuity, access and flexibility

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Shifting the balance of care from hospital to the community is a key challenge within Delivering for Health (Scottish Executive, 2006). This continued drive for community based services should hopefully encourage better and more connected services within the community and provide better collaboration between services. The Scottish Recovery Indicator work which is in development at present will help generate best practice examples of care.

Additional attention to the provision of activities, techniques and therapies that create opportunities for people to access and maintain resourceful states would enhance their range of coping and recovery strategies, especially if there was a coherence and consistency between the services, treatments and supports received in hospital and those they are supported with on discharge.

Quicker, more consistent and flexible access to services with fewer gatekeepers and more commitment to providing agreed continuity of support and continuity in personnel is needed

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in many services, but most particularly in psychiatric services. Support needs to be more flexible and responsive to people re-establishing themselves. Where such support is offered in a timely and effective manner, it can promote recovery and reduce longer term need for support. We hope this report leads service planners to consider how they can provide services which ensure the flexibility and continuity that people in recovery told us they need to maintain their wellbeing.

## Medication

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It is clear that a shared decision making approach to treatment and medication – a therapeutic alliance – should be promoted in situations where professionals can mandate treatments that conflict with the desires of clients. This alliance is clearly preferred by narrators and person-centred clinicians.

Overall, our narrators belonged to four schools of thought regarding medication, although they were not mutually exclusive. The first believed that there was no way they could have recovered without medication. The second believed that the process of getting the right medication was complex and had many problems and should therefore involve the service user in the management and evaluation of medication. The third felt that the side effects were so debilitating that they were not worth enduring and in addition, the only reason medications were used was to make individuals 'fit in' to society. The final group equated recovery with living medication free.

The key issue arising from the narrators, regardless of which of the four schools they subscribe to, is that they should have a prime role in the decision making, management and evaluation of their own medication whenever possible. This not only allows them to better manage the side effects and establish responsive regimes but also addresses the issues of power and disempowerment, rights and self-determination, and self-esteem.

## Treatment and supports

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This research adds to the growing body of research, good practice examples and guidance around what types of services support people with long term mental health problems to recover. Promoting access to these services and treatments requires recovery focussed staff and the willingness to support people through their individual recovery journeys to meet their hopes and aspirations. Since a recovery indicator tool is being developed in Scotland to monitor the service level recovery orientation of different agencies and organisations, dissemination of best practice potentially has an important role to play in the implementation of recovery-oriented practice throughout Scottish services.

Although alternative and specialist therapies have proven to be popular and successful with our narrators, access to these therapies through the NHS is currently not consistent. Narrators have shown that they are keen to try out different non-pharmaceutical methods of managing their states of wellbeing and this should be supported and reflected in regional health services through increased consumer choice. Several narrators recounted that the right combination of therapies enabled them to reduce their reliance on pharmaceutical combinations.

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## Professional helping relationships

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Much of what is discussed by our narrators is quite common in ordinary human relationships – the need to feel respected, to be able to trust and share hope and communicate reciprocally with others in a non-threatened way.

The development of a helping and supportive relationship with professionals was often a pivotal turning point in narrators' journeys. Our narrators regarded demonstrations of empathy, trust, collaboration, shared power, respect, personal investment and kind gestures as most helpful in their treatment relationship with mental health professionals. These findings replicate findings from Borg and Kristiansen (2004) and Schinkel and Dorrer (2006).

Narratives do, however, show great variation in the quality of professional relationships experienced. In many ways this reflects the variation one would expect to find in human interactions, particularly where the relationship is founded on an unequal 'service provider/ service user' basis. However, we believe that the helping and hindering role of supportive relationships in recovery warrants increased emphasis in the recruitment and training of mental health professionals. In addition, it suggests that service users should be enabled to identify where they do not feel that a relationship with a professional is helpful to their recovery.

A central determinant of whether a relationship with a professional would be helpful to recovery was the attitudes and values of the professional. Narrators clearly identified the importance of working with people who believed in their potential for recovery and who relayed a positive message of hope, perhaps most importantly at initial diagnosis. We believe this provides a clear message to planners, policy makers and practitioners alike around the need to emphasise the key role of attitudes and values in mental health service provision.

The Royal College of Psychiatrists has begun to incorporate a recovery ethos into its work (K. M. Berzins, 2005). Consultant Psychiatrists are now being encouraged to deliver effective person centred care in mental health (Royal College of Psychiatrists, 2005). This will undoubtedly support recovery for clients.

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## Housing

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Agreeing with the Canadian South West Mental Health Implementation Task Force (2002), it is the view of the authors that a continuum of community-based housing with supports, additional community support and private accommodation must be safe and affordable and must provide flexible interventions that respond to individuals changing needs to support recovery.

Housing support organisations' contributions have been valuable to individual recovery journeys in various ways from providing shelter to encouraging responsibility for self and others.

Although Local Authorities have strategic responsibility for assessing and meeting housing needs of citizens recovering in the community (Blackman & Harvey, 2001) homelessness was still an issue that confronted several narrators at intermittent periods throughout their lives. Findings from the New Zealand Mental Health Commission that indicated the importance of housing to self-esteem and community integration were shared with this study. Similarly, several of our narrators experienced losing their homes due to ill health and as a consequence

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financial insecurity or extended hospital stays. Increased attention to ‘exit needs’ for individuals whilst in hospital should be addressed to help ease their community transition and to ensure individuals do not lose their homes or other resources (jobs, friends etc.) through ill health, loss of income, community stigma or lack of support to maintain their residency.

Services and benefit systems should not discriminate against those who own or rent their homes but should provide flexibility in support to reflect the diverse population of individuals in recovery from mental health problems. It is also crucial that those people that do not have homes be assisted to establish them and those medical decisions, benefits and support services do not undermine people’s ability to decide on where and how they want to live.

It is important that support in the acquisition, establishment and maintenance of a home is designed around the needs of the individual, taking into account their preference for supported, communal or independent living and acknowledging that this preference may change over time. Support services that provide a responsive, on demand service allow individuals to embark on a recovery journey with an element of security.

## Financial supports

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It is more difficult for people to develop and navigate a recovery path when resources are low and income is insufficient. Financial security or insecurity impacts on individuals’ lives in fundamental ways. It can determine diet, health, levels of social participation, where and how they live, and the maintenance of social and family networks, working patterns and aspirations and planning for the future.

The transient and invisible nature of many mental health problems means people are often open to scrutiny and having to prove their mental ill health when least able to cope with such scrutiny. Clearer concise claims processes with definitive criteria for applicability would solve some application related stresses.

Fear of benefit removal hinders people’s recovery. Since risk aversion is a primary problem for many people with mental health problems the risks involved in transition from benefits to work need to be further reduced. As discussed in our previous chapter on engagement, income support policy is slowly beginning to recognise the intricate nature of recovery and mental health problems. As such, legislation now allows for individuals on incapacity benefits to return to their former benefit level if they become ill again within two years of returning to work. This generic rule should in principle encourage and support individuals back into employment without risking loss of benefit upon recurrence of ill health problems.

## Conclusion

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Although narrators were mostly positive about treatment and supports they argued that supports need to be more responsive to the changing and diverse needs of individuals. Many believed that more heterogeneous services would help recovery and that current services should be more recovery focussed in their availability, design and practices.

External factors such as the availability of necessary or desired treatments and services, financial pressures, the availability of support from outside services such as housing, fear of fluctuating benefit income, the perceived stigma and isolation of mental health problems, and the fluctuating nature of these problems often had to be addressed and managed in order to further individuals recovery journeys.

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It is difficult to construct common descriptions of individuals' unique recovery experiences. However, with a growing body of evidence, it is now widely recognized that people who have serious mental health problems can participate actively in their own treatment and recovery and can become the most important agent of change for themselves (Mueser *et al.*, 2002). Allies and accomplices who are recovery focused have been found to help individuals move towards recovery with astounding resolve. Professionals who show a deep commitment to individuals (over time), using their knowledge, but also learning from and respecting individuals facilitated recovery. Access to the right resources and services at the right time can also facilitate this process.

In some ways our findings around treatments and supports reiterate what many people have been saying for some time, i.e. that person-centred services help people lead fuller lives and better promote recovery. It is perhaps the fact that this message is not new which suggests that we have some way to go before we have a service system which works to the satisfaction of all stakeholder groups, as acknowledged in *Delivering for Mental Health*. What the narrative research offers is fresh evidence to support the development of recovery-oriented treatments and supports in Scotland and a powerful endorsement of many recent developments in policy and strategy.

Beyond mental health services there is work to be done to enhance capacity and opportunity for people to help themselves and their peers. Throughout this research narrators have identified the broad range of skills and strengths which people in recovery gain. Better harnessing and formalising these strengths, through, for example, self-management and awareness programmes, could help us reduce the demands on formal services, promote self-direction and responsibility and achieve better outcomes.