



For New Beginnings



Oh dear! The goose is in the bottle
How shall we get the goose out of the bottle?
The goose *is* out of the bottle!

RECOVERY IN NSF

‘Wild Geese’

A Report on a six months Consultancy on the Recovery Approach

For

National Schizophrenia Fellowship

And carried out by

Green Gauge Consultancy

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EXECUTIVE REPORT

Mental health is crowded with theory in the shortage of reliable evidence and contested facts. What, for example, causes schizophrenia? We don't really know.

There are three paradigms of modern care:

- Medical: we can cure you/we can treat you
- Social: you have needs which we should meet
- Recovery: I have a problem, but with help I can grow beyond it.

This report looks in detail at Recovery as a relatively new paradigm, drawing on a six months consultancy across NSF.

The main ingredients of Recovery Approach are:

- Belief by the person with a mental illness that they can and will recover
- Belief by people helping them, including professionals and carers
- Commitment by the person with a mental illness to recover
- A strategy for recovery
- Resources to enable the person to recover
- Personal growth is shared with others seeking to recover.

Recovery, used in this sense, does not require medical cure. Nor does it require people to stop using medical or social care services. It is about the capacity to lead a full life not dominated by illness or treatment only. Stephen Hawkins has a profound and deteriorating physical disability, but this does not negate his contribution to science. Some people recovering from mental illness state that the disability has increased the depth and reach of their lives. Out of adversity can come personal growth. This is in contrast to the predominant unwritten and unspoken belief in other understandings of mental illness that people never recover. The key messages from the consultancy period include the following:

A welcome debate. People using services, carers, members and staff across NSF welcomed debate on the Recovery Approach.

People have already made a recovery. It has been important to discover how many people have made their own recovery. Many want to share this experience with others, for the benefit of others. Many people in contact with NSF have already found a great deal of hope through their experience of recovery, but have not had a platform to express this until now.

Some people are not yet ready for recovery. Other individuals were interested and excited by the possibilities of the Recovery Approach, but did not feel ready to embark on the process. They located themselves at the stage before this.

Setting the direction for recovery, but do not leave anyone behind. There was a sense that the organisation, as well as individuals, need to undergo the process of recovery as well, because this affects staff as well as users and carers. They also need to make a journey out of a culture of maintenance and dependency, little hope and low expectations. There was a readiness amongst staff and people using services to move in the direction of a Recovery Approach, but not to leave behind those who continue to require “good maintenance”.

Get to the same position nationally. The level of engagement of different geographical areas with the Recovery Approach during the consultancy period has been variable. Some areas have had no significant engagement. Other areas are probably ahead of the organisation in implementing a Recovery Approach in local services. Some teams are eager to have the tools that will allow them to get on with the job of implementing a Recovery Approach. Other teams are still struggling to see how it might be applicable to their specific area of practice.

Recovery and black and other minority ethnic communities. There is still much work to do on articulating the Recovery Approach from a black and minority ethnic

perspective. The Recovery Approach concentrates on the “lived experience” of people who use mental health services and this is significantly different for minority ethnic communities in the UK. However we are hopeful that these communities will find in the significance given to lived experience an echo of many of the messages the black and minority ethnic communities have already delivered to mainstream society on culture and identity.

Message for campaigning. The recovery model poses a direct challenge for NSF, because our campaigning has often been for the provision of good maintenance services. We have not always had a higher horizon than seeking improvements in the current set of mental health services in the short-term, to correct urgent deficits that blight the lives of our beneficiary group here and now.

Message for Membership and Voices. The origins of NSF and its organisation through self-help groups has common ground with the self-help methods developed in the Recovery Approach. Voices could have an important role to play in developing self-help groups.

The message from NSF to the Recovery Movement. The Recovery Approach has a great potential to improve lives and provide an inspiring vision for mental health services and for those who work in them. However, it must not become an ideology imposed on people living with serious and often painful conditions. It must never impose a burden of unrealistic expectation on people already struggling with stigma, disability and illness. It will only be valuable if it works for everyone who uses mental health services, including people who live with serious continuing disability, valuing small steps towards a fuller life, as much as the outwardly larger steps which other people may take, such as getting an ordinary job or living in ordinary housing.

The following report describes what has resulted from the debate across NSF and makes many specific recommendations, which can be summarised under five headings: training, tools for recovery, alliances, information and changes focussing on practice.

RECOVERY IN NSF 'WILD GEESE'

1. INTRODUCTION

This report is to set out the findings of a six month consultancy into the Recovery Approach and to map the way forward. The aims of the consultancy were to:

- Improve our understanding of the Recovery Approach for NSF services, with particular attention to front-line staff and service users
- Define the steps NSF should take in order to develop the Recovery Approach in its' services and develop momentum which can be sustained after the consultancy period
- Describe suggested ways of communicating and promoting the approach within NSF and externally

The purpose of this report is to present the findings of the six months consultancy into the Recovery Approach, to offer recommendations on the basis of these findings and provide a framework for incorporating this approach into the work of NSF. During the course of the consultancy period most people welcomed discussion of the Recovery Approach and its implications. So the initial challenge of bringing about a cultural shift in the organisation was not the hurdle we expected it to be.

During the consultancy it was possible to listen to many people who have gone through a personal process of recovery in their own lives. This has been the most rewarding part of the work. It has greatly shaped the ideas contained in this report. Conferences, Members' Days and Staff Meetings provided important opportunities to listen to a wide range of people. Ron Coleman and the Keepwell Team, based in Gloucester, provided an invaluable resource. Time spent with members of this team was always stimulating, continually providing new insights into the recovery process.

Recovery reflects the lived experiences of real people. They own these experiences. Those of us who wish to learn from them and celebrate the hard won outcome of their struggles, need to be true to the spirit of these pioneers, to their struggles and their generosity. Much of the work that has gone into making this consultancy a rich and fruitful process is based on their experiences. It included meeting Alison Cox, Phillip Hill, Nick Shipley, Tim Cuss and many others who have taken control of their lives and become 'victors'². It was also possible to meet some of the 'heroes' who have survived for over thirty years, often in spite of mental health services. They had to find their own ways to manage their distress, often unknown to the people who have formally 'cared' for them.

² "Victim to Victor I, II and III". Handsell Publishing.

This has not been an academic project, but many books and papers related to the subject have been referred to (see Bibliography). We are grateful to Piers Allott at the University of Central England, who has been an inspiration in shaping this final report. A pilot course on Solution Focused Coaching was run for a number of staff, to assess the applicability of Solution Focused skills to the recovery process (see Appendix 3). Commissioners of mental health services and other funders were keen to talk about recovery. They are interested in the idea of recovery, especially about new outcomes that take users beyond mental health services, but many remain sceptical until they can see practical results. Some potential allies have been identified through the consultancy period. These people take the lead in the development of a recovery culture, within the user movement and amongst professionals.

During the consultancy many people wanted to discuss the language adopted by the Recovery Movement. The word ‘recovery’ itself was a particular concern as people often associated it with a medical cure. People struggling to better capture the meaning offered us a variety of alternative words³. We did not replace the word recovery in this report, because it would divert attention from ideas already developed. It would amount to constructing new theories, which could be confusing and divisive. It could also become a means of avoiding the decision about whether or not NSF associates itself with the Recovery Movement. As we shall see below, the Recovery Movement itself is aware of concerns and limitations about the word, but is united in a common understanding.

This consultancy considered recovery as it applies to the operation of specific types of services. Residential care, in particular, presents significant challenges to the adoption of a Recovery Approach. The opportunity to discuss these issues with staff and residents at Dogpool Lane, Birmingham, was particularly appreciated. A recent research study, “Assuring Quality Housing and Support for Walsall Residents with Mental Health Needs”⁴ also provided useful insights into how users view these services.

A series of eleven newsletters ‘Recovery So Far’, tracing the flight of the goose, have been widely circulated across NSF during the consultancy. These attempted to set out some of the principles of recovery and emerging ideas, to provide some tools, examples and approaches staff could use to develop the Recovery Approach in their locality. An opportunity arose for individuals using the day services in Bristol to attend a “Recovery Week” at Forresters. Twelve people attended. It was a valuable and formative experience for everyone who took part (see Appendix 4). We hope they will be able to assist the development of one of the pilot schemes and contribute to developing recovery skills and tools for use across the country.

Presentations have been made to each of the three Operations Teams in England and to the NSF team in Cymru. We hope this contributes to the process of embedding recovery into the organisational culture, the stated aim of NSF’s Three Year Plan. We also took

³ Including: Rehabilitation, Restoration, Restitution, Regain and Reclaim.

⁴ Paul J. Carling & Piers Allott. “An Action Research Report Prepared for Walsall Social Services”. Published by University of Central England in Birmingham, Centre for Mental Health Policy, September 2000.

opportunities to present the Recovery Approach in the induction of new staff. It was encouraging to see how enthusiastically this was taken up by participants.

It is important that NSF remains true to the principles that inspired individual people to take control of their own lives. NSF's mission needs to reflect the aim to support people to determine their own lives, free from those who would seek to limit their citizenship and social inclusion. Much of the activity within many NSF services represents steps on the way to a Recovery Approach. It is not necessary to start all over again. We must celebrate our achievements, but recognise there is still more to be done. This report makes a series of specific recommendations to support the implementation of the approach.

2. WHAT IS RECOVERY?

“Recovery is proving to be the most powerful and far-reaching paradigm in the mental health field today”⁵. The Recovery Approach has grown out of user movements around the world, starting in America. Recovery is already a major influence in shaping mental health services in America, Canada and New Zealand. Twenty-six American States have committed their mental health services to a recovery ethos. In New Zealand the Recovery Approach has been adopted as the national mental health strategy. Recovery is widely accepted as the standard for best practice.

This section describes recovery in the words of its pioneers. We also consider recovery as a compound, made up of a number of distinct elements that are bound together.

2.1. Important Messages

“There are a number of things I tell students about how to work with people who appear to be hard of heart, apathetic, and unmotivated. First I help the student understand the behaviour in terms of its existential significance. I want the student to grasp the magnitude of what it is they are asking a person to risk when they ask them to start to care about something again. It is not a crazy thing to try to protect such a vulnerable heart. Secondly, I ask students to suspend their perception of people as chronic mental patients and try to see the individual as a hero. I ask them, could you have survived what this individual has survived? Finally, I try to help students understand that although they do not have the power to change or motivate the person with a psychiatric disability who is hard of heart, they do have the power to change the environment, including the human interactive environment, in which that person is surviving. When working with a person with psychiatric disability who is hard of heart, who has given up and who is motivated not to care anymore, we must understand that this is a person who feels they have no power. They experience all the power to be in the hands of others.”⁶

⁵ Dr. P. J. Carling, Piers Allott, Mike Smith & Ron Coleman. “Partnerships in Mental Health, Directional Paper 3: Principles of Recovery and For a Modern Community Mental Health System”. This is one of five Directional Papers produced by Carling and Allott for the NHS Executive West Midlands.

⁶ Pat Deegan. (1996). “Recovery as a Journey of the Heart”. *Psychiatric Rehabilitation Journal* **19**, 3, pp 91-97.

“Recovery is a process, a way of life, an attitude and a way of approaching the day’s challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration to live, work, love in our community in which one makes a significant contribution.”⁷

“Clinicians often ask us, ‘What about people who aren’t interested in recovery, and who have no interest in peer support and other recovery concepts?’ What we often forget is that MOST people find it undesirable to change. It’s hard work! People have gotten used to their identities and roles as ill, victims, fragile, dependent and even as unhappy. Long ago we learned to ‘accept’ our illnesses, give over control to others and tolerate the way of life. Think how many people live like this, in one way or another, that don’t have diagnosed illnesses. It’s easier to live in the safety of what we know, even if it hurts, than it is to do the hard work of change or develop hope that can conceivably be crushed.”⁸

“We are aware that what we are proposing is a radical shift; it means leaving the bunker mentality of the established mental health professions behind and being open to new theories and philosophies with their own treatment options. It is, however, a shift we will have to make sooner or later, if we really want to help people take control over their own lives.”⁹

“The Recovery Approach recognises that each individual uses a very diverse set of strategies unique to each person, to achieve community inclusion after experiencing major mental health problems. It acknowledges that many individuals use few or even no professional mental health services, using a recovery orientation differs markedly from a traditional one.”¹⁰

“I want myself as I am. Accept myself. I like myself now. I like my honesty, my truthfulness, the fact that I can, if people tell me things, keep a secret. The fact that I am respectful to people. Just lots of things. It’s time to do things for me, and to look after me and to love myself.”¹¹

“I am not recovered. There is no repeating, regaining, restoring, recapturing, recuperating, retrieving. There was not a convalescence. I am not complete. What I am

⁷ Pat Deegan. (1998).

⁸ Mary Ellen Copeland. “What Recovery means to Us”. www.mentalhealthrecovery.com/read13.html

⁹ Prof. Marius Romme & Sandra Escher. “Making Sense of Voices”. Mind Publication, 2000, p.128.

¹⁰ Dr. P. J. Carling, Piers Allott, Mike Smith & Ron Coleman. “Partnerships in Mental Health, Directional Paper 3: Principles of Recovery and For a Modern Community Mental Health System”.

¹¹ Susan Butler. “Susan’s Story” in *A Gift of Stories* gathered by Julie Leibrich. The University of Otago Press.

is changing and growing and integrating and learning to be myself. What there is, is motion, less pain, and a higher proportion of time well lived.”¹²

“I really do not want to be called recovered. From the experiences of madness I received a wound that changed my life. It enabled me to help others and to know myself. I am proud that I have struggled with God and with the mental health system. I have not recovered. I have overcome.”¹³

“When statutory and voluntary mental health services at last begin to realise that users are citizens first, friends and loved ones second, employees and enthusiasts third, and users of mental health services fourth or fifth, then all our imprisoning laws and relationships change. Then users make real friends with a neighbour, or fall out with a barman at the local pub.”¹⁴

2.2. The Recovery Compound

The Recovery Approach can be likened to a compound made up of a number of elements:

Recovery is an *organising and generative idea*

Recovery challenges us to reorganise the way we support people. It provides an understanding the experience of mental distress (without necessarily identifying or debating causes).

Recovery is an *underpinning vision*

This vision is important for people who use services, their carers’, families and friends since it offers some realistic measure of hope. Recovery is important to people who use services, because it is an approach that has been appropriated by service users. Users are at the centre of recent developments in the Recovery Movement.

This vision can help staff understand how different parts of a system can work together. Otherwise much of what is already in place can appear partial and piecemeal. New developments can appear to be only more parts and mechanical additions, rather than adding to a consistent approach. This element can help motivate staff by providing a sense of value and belonging.

Recovery is a *movement*

It is important to accept that the Recovery Movement has been developing over some time. Users have been central and active in this movement in a way that they have not

¹² S. Caras. “Reflections on the recovery model”. Unpublished, 1999.

¹³ “The Wounded Prophet” in *Recovery: The new force in mental health* by S. Clay. Columbus Ohio: Ohio Dept. of Mental Health, 1994.

¹⁴ Peter Bates. “Stuff Dreams Are Made Of”. *Health Services Journal* **33**, 4th April, 1996.

been in other approaches, models or understandings of mental health and illness (e.g., in the medical model and the social care model)¹⁵. While a good deal of the aspirations and mission of NSF finds common cause with this movement (e.g., around choice, support and realistic hope) it is important to recognise and accept the provenance of the Recovery Approach. We must respect this and find the means to work collaboratively, rather than appropriating and alienating other established voices and potential allies in this movement. The value this organisation can bring to the Recovery Movement is its scope and influence. No other organisation has yet made this analysis of the implications of recovery, although again it is important to accept other mental health organisations have already undertaken some very valuable work in this area¹⁶.

Recovery is a *journey*

As Ron Coleman makes clear, people are the building blocks of recovery, and the cornerstone is the self. It is essentially an individual personal journey. Only some parts of that journey can be shared with others. This journey is a hard path. Not everyone will want to tread down it. Acceptance that there is a problem is a crucial starting point. This can be a difficult and hard-won acceptance, involving a lot of personal pain. Our organisation needs to find ways of supporting people on this journey, but also needs to retain a sober and realistic account of our abilities and limitations. If we are part of that journey, we can be there by invitation only. There are some key tools that can help. This report will have more to say on their development and application and the part NSF can play. Because not everyone will tread down the recovery path, NSF needs to find a balance between the *need to support people who want or need to stay where they are and supporting people on their recovery journey*.

Recovery is a *prize*

Many people involved in the Recovery Movement are convinced of the importance of this approach. But it would not be appropriate for this organisation to impose an ideology of recovery. Many users NSF support have the most enduring and disabling conditions. The challenge has been to discover whether the Recovery Approach is just as valid for individuals experiencing serious and enduring mental health problems. The prize, if this is the case, is that embedding the Recovery Approach within NSF will enable some people to move beyond life in close contact with the psychiatric system and mental health world, but empower everyone who uses our services, and those who support them, to have greater determination and control of their own lives.

Because recovery is a big and complex compound, it is important to keep in mind and to at times separate out these primary elements. Together the whole compound has a value in helping us understand two other important social issues. This report will only be able to touch on *social exclusion* and notions about *community*, but recovery helps us to understand the connection of mental health to these wider social issues.

¹⁵ The Recovery Approach is an inclusive approach in that it accepts the individual's understanding of their own distress. This may be medical, social, psychological, spiritual, etc.

¹⁶ For example the Mental Health Foundation's "Spiral Programme" from autumn 1999. Spiral News. www.mentalhealth.org.uk/spiral

3. FROM MAINTENANCE TO RECOVERY

3.1. The History of Recovery

The Recovery Approach has a longer history than is at first apparent. Dr. Abraham Low, an American psychiatrist developed the first Recovery Approach at the end of the 1930s, when he observed the need for some structure to continue to provide support to patients discharged from the hospital setting. He envisaged the formation of self-help groups of ex-patients. The earliest self-help group was started in November 1937 and comprised of thirty former patients of the Illinois State Psychiatric Institute. Dr. Low closely supervised this and other recovery self-help groups through establishing an organisation known as Recovery Incorporated, which still exists in Chicago today. Dr Low remained medical director of this organisation until 1952 and continued to develop techniques and training to allow the self-help groups to become independent, secular lay groups without professional supervision. This method of organisation by self-help group finds an echo in NSF's origins.

Dr. Low set out a systematic method to be followed during self-help meetings that were composed of four "steps". These are similar, but not directly associated to the '12-step recovery program' latter developed by Alcoholics Anonymous (AA). From the outset, Dr. Low believed and maintained that there were "no hopeless cases". Some of Dr. Low's core principles around *reacquiring self-leadership*, *overcoming fear* and *strengthening self confidence* find an echo in the present day Recovery Movement. Through participating in lay self-help weekly group meetings members sought and obtained the help of fellow members. There are now estimated to be over 700 recovery groups meeting in the US, Canada, Ireland, Wales, Spain, Israel, Puerto Rico and the UK. Recovery has become the national mental health strategy in New Zealand.

The significance of the development of self-help groups included the development of a user only space and repositioning their experience as the focus of attention, rather than the search for a cure or religious meaning, or the role of expert being given over to a professional group. The growing user movement in the US took up the ideas of recovery and appropriated them. It became allied to the US Disability Rights movement, which has a strong historical and cultural self-help ethos. This is evident in other US mental health developments, such as the development of the Clubhouse Movement. The shared aim was to stimulate users of services to take greater responsibility for themselves, to communicate with one another, to offer assistance and information and to improve the position of the user or consumer. Current key figures in the US Recovery Movement include Pat Deegan¹⁷ and Mary Ellen Copeland¹⁸.

With a few notable exceptions, the UK did not develop a strong mental health self-help or user movement. The main development in the post-war period was the anti-psychiatry

¹⁷ See for example, "Recovery as a Journey of the Heart". *Psychiatric Rehabilitation Journal* 19, 3, pages 91-97, 1996.

¹⁸ See for example, "What Recovery Means to Us". www.mentalhealthrecovery.com/read13.html.

framework associated with Dr. R.D.Laing. This was very much a flower of the sixties that lost its bloom by the middle seventies. It corresponded with the loss of optimism about finding a cure for conditions such as schizophrenia in mainstream psychiatry. In the 1980s Marius Romme, a Dutch psychiatrist and Sandra Escher, a journalist, started to organise conferences for voice hearers¹⁹. This led onto research with “voice hearers” and conferences in the UK, which led to the development of the National Hearing Voices Network. The Network has a self-help group format, similar in some respects to Dr. Low’s earlier approach. This has been empowering for many users, including Ron Coleman, who has become a key figure in the Recovery Movement in the UK²⁰. Other important UK developments have happened in the West Midlands, including a number of recovery-orientated projects and conferences²¹.

3.2. Current Mental Health Service Context

Modernisation and social exclusion

Government policies appear to be changing the ethos of mental health care. The commitment to tackling the links between poverty, unemployment and mental illness, leading to policies that focus on disadvantage and social exclusion, has been welcome. People who use mental health services, and their carers, are among the most excluded members of society. The social exclusion agenda is important, but there is less development of what would constitute *social inclusion*, when it is expected to appear as a significant social feature, and how it will be recognised and evidenced.

To date the agenda around race and mental health has not been directly tackled. There are now concerns that values as well as evidence will require examination in developing and providing mental health services; that the risks of taking up treatment as well as benefits will be of increasing interest to people using services. This is at the time people using services have more avenues for information, if not greater rights.

Risk

Risk is the predominant currency in mental health services. It is invariably perceived as a negative element, to be reduced at all costs within the practice of mental health services, for public safety reasons and for the welfare of the service user. But this understanding of risk ignores the function of risk as the mobilising dynamic of change in our larger social structures. Where there is no risk then we get a fixed, unchanging state. Risk aversion in mental health services may in part explain the lack of a dynamic relationship between these services and users and other elements of the social fabric. It may explain the lack of innovation or rapid change.

¹⁹ See Professor Marius Romme & Sandra Escher. “Accepting Voices”. Mind Publications, 1993.

²⁰ Ron Coleman has summarised his approach to recovery in his book: “Recovery an Alien Concept”. Handsell Publishing, August 1999.

²¹ For example, the West Midlands Recovery Network and the Anam Cara Crisis House, Birmingham, operated by CHANGE

Local responses to national policy

To date, the national mental health strategy²² has focused upon risk and a public safety agenda. The aftermath of inquiries into homicides has led to defensive psychiatry and mental health practices. Implementation of the framework has concentrated attention on the *form* of services as much as *content*. The implementation of the framework can appear to be mechanical. The types of evidence cited in the framework continue to put medical research at the top of the evidence-base. The Department of Health is mindful of the risk it runs in being over-prescriptive in its definition of services, with the evaporation of local initiative, ownership and leadership. There is concern that a compliance and maintenance culture has been reinforced by assertive outreach teams, the main new form of mental health service, provided by statutory services and established since the publication of the framework. Little new mental health money has moved beyond statutory services, which have been under-funded for many years. These soak up any new resources without noticeable differences or improvements being made to the experience of people using services and their carers. A “patch and fix” approach characterises the use of new investment locally, rather than the emergence of innovation.

Capacity problems and structural change

There is a national workforce capacity problem, with insufficient nurses, social workers and psychiatrists to deliver the framework. There are also concerns that not all of the targeted money for mental health has been allocated. It may also be the case that ring-fenced money for mental health has enabled some health and local authorities to divert previous allocations from their core budget away from mental health. Statutory services are preoccupied on their own organisational futures, especially NHS and social services reorganisation following the publication of the NHS Plan²³.

Profile of people using mental health services

The profile of people who require mental health services is changing. People using mental health services are younger, with no history of longer-term mental hospital in-patient admissions. They are more likely to use drugs and alcohol and to identify with their own cultural and peer groups. The perception of mental illness within these groupings has a significant effect on the use or avoidance of mainstream mental health services. There are generally higher expectations in relation to independence and quality of life than a generation ago and an expectation to see services operate with a consumer-orientated approach. Mental health services, like the NHS, struggle with meeting these expectations. Research shows early intervention has better outcomes over the longer-term, but most young people will actively avoid services that are controlling and stigmatising.

²² “Modernising Mental Health Services: safe, sound and supportive”. December, 1998.

²³ The NHS Plan – A plan for investment. “A plan for reform”. July, 2000.

There is some evidence that families and carers, who have been locked out of mental health services for many years, are starting to be recognised in their own right, but most services are poorly prepared to work with them or have a poor understanding of their needs.

A new vision for mental health?

There is currently a lack of an underpinning vision for mental health. Increases in the level of financial investment and increases in the number, and skills, of the mental health work force, if maintained in the medium-term, may foster some optimism. This will not, by itself however, generate a new vision for mental health services.

Some commentators believe we are in a transitional period, moving *from* an institutional and facility-based service delivery (where service users require comprehensive support system mainly from specialist service providers) *to* an era that will value people first and primarily as citizens with the potential for, and a right to, full participation and integration. This may indicate the value of the Recovery Approach to the larger mental health context.

Psychiatry has been described as being in a state of despair in regard to understanding psychosis over the last century. The medical model has a very gloomy prognosis for people with a diagnosis of schizophrenia and other enduring conditions. The emphasis has been to suppress the symptoms people experience and to develop a range of approaches that are designed to protect the public from the ‘potential dangers’ of these erratic and unpredictable people. Some of the ‘treatments’ have been barbarous, despite the ‘humanitarian’ views of the perpetrators. To be injected with rats’ brains and strapped into a bath for 24 hours, are just a couple of the documented forerunners of a “hit and miss” approach to the treatment of people whose humanity and dignity has been routinely stripped away.

3.3. Contrasting Approaches

It has been helpful to contrast a maintenance approach, that has dominated psychiatry over the years, with the emerging recovery approach. This has helped to convey the type and scale of changes required. It is a challenging contrast, but necessary, if we are to be aware of the limitations of the current approach, and the distance we have to travel to develop a new, and hopeful, culture in psychiatry and mental health services.

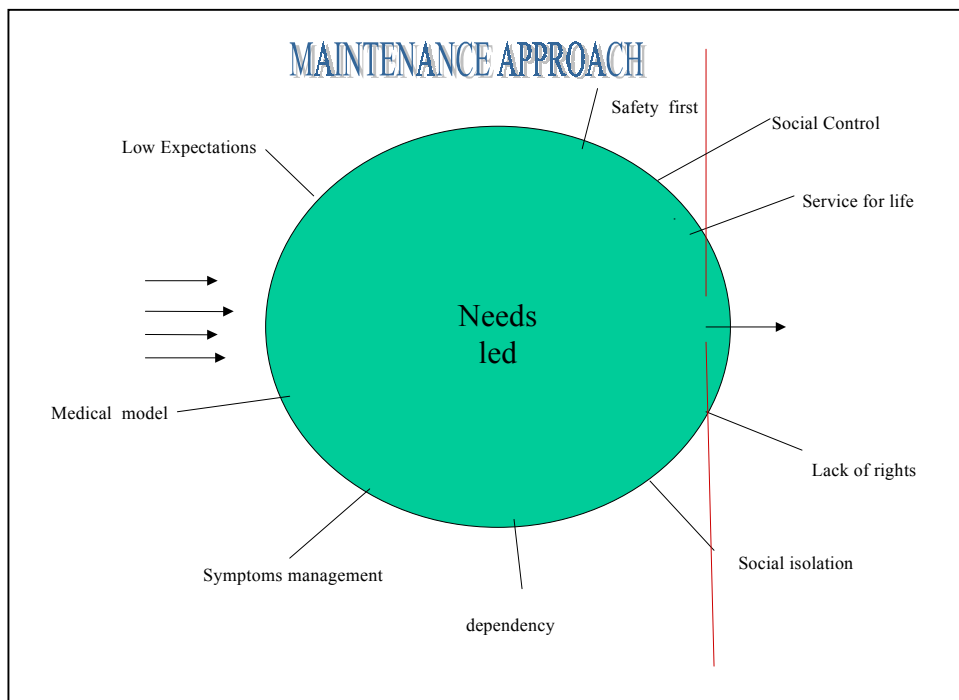
The Maintenance Approach

A ‘Maintenance Approach’ can be represented diagrammatically as shown in Diagram 1. These services are dominated by a culture of very low expectations. It is assumed that users need services indefinitely. Staff are an extension of the medically orientated Community Mental Health Teams. They reactively report on any negative changes or problems requiring changes to treatment. Risks are discouraged on the grounds that when people are put under pressure they are likely to relapse (medical and stress models

of mental health provide the rationale). The service sees itself as providing a resource for the ‘safety’ of the community. There are usually written referral criteria to ensure people who are entitled to the service access them but there is no ‘pressure’ on anyone to move on. A few people will move on, but in many instances this is discouraged, because of the prevalent ‘risk management’ culture.

Services are under continuous pressure, coping with the demand to provide more and more users with services indefinitely. The tactics used to reduce these pressures are: (a) to raise the service entry level criteria, so that only those assessed with the highest level of need get any service, and (b) to invest more and more resources to expand the team. Both tactics are difficult to pull off in practice. Even if they work in the short-term, pressure will build up again. Because no attention is given to anything beyond this approach, the focus is maintained on harm and risk and there is no internal change to the professional outlook. The only solution is to expand through soaking up all new resources that can be found, but this cannot be sustained indefinitely.

Diagram 1 illustrating the ‘Maintenance Approach’



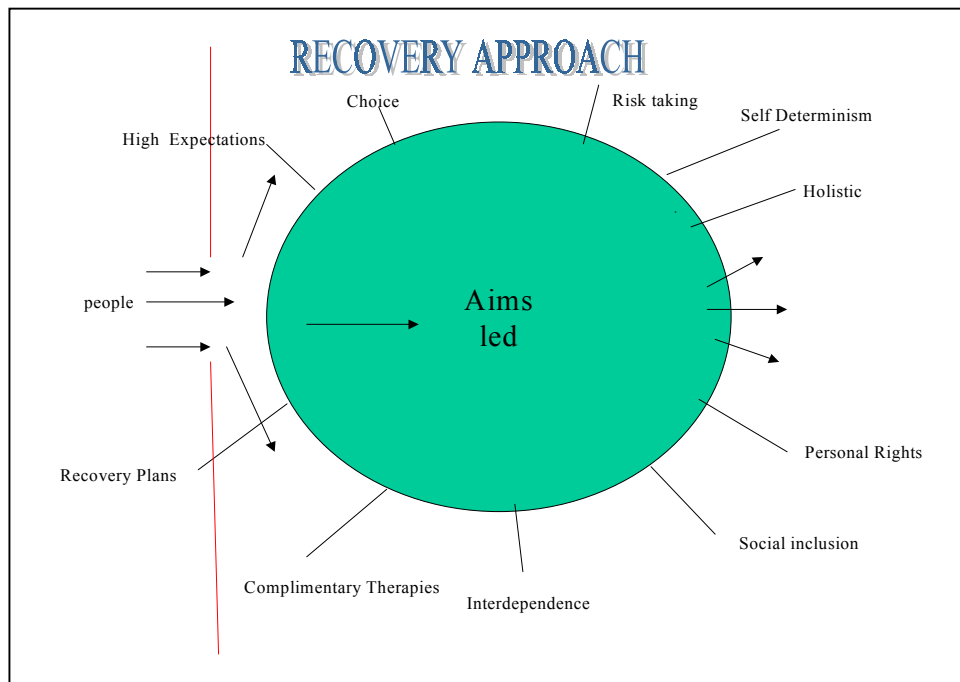
The Recovery Approach

The ‘Recovery Approach’ can also be represented in the diagrammatic form below. In this model, emphasis moves towards keeping people beyond the ‘service’. The red line represents a barrier that is used to ensure alternatives to entry are discussed *before* people enter, trying to ensure that people use formal mental health services to a therapeutic minimum. This is done not to manage demand on professional teams (as is necessary in

the maintenance approach) but to provide support, to help people using the service keep their employment, continue their relationships, and make choices that retain their involvement and fixture in their own community. If people need to use the service for a longer period, they enter a service with a conviction that they will ‘recover’ and move on. The service has a duty to maintain ordinary community links and access these resources.

People will try different approaches, take risks and retain an ability to make choices about their own lives, even where they have substantial and enduring disabilities. They are supported to take control of their lives and be a part of their communities. They will have the opportunity to learn about themselves, their mental health and illness, how to keep well and to negotiate difficulties. The ‘Recovery Approach’ represents the struggle of ‘hope’ over ‘despair’.

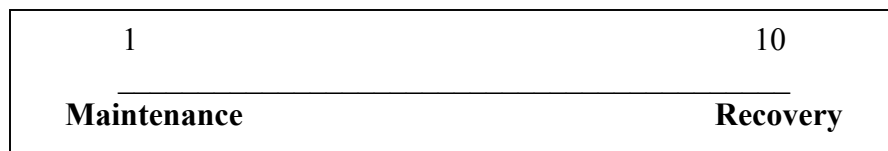
Diagram 2 illustrating the ‘Recovery Approach’



Recovery is a journey that is unique to every individual. Consequently it is better thought of as an ‘approach’ rather than as a formal ‘model’. It is an inclusive and a pragmatic approach. It recognises different people will find different routes. Treatments and interventions provided by the medical, social, psychological and other practitioners will be useful on *their* journey. It is, however, the person who exercises choices over these matters in the context of rights and responsibilities.

From Maintenance to Recovery

Services supporting people may begin to understand where they lie in the maintenance approach a recovery approach *continuum* by monitoring their performance on a 1 to 10 scale.



The road to recovery for services, can be started, by the staff and the people using the service separately asking themselves where they think the service is on this scale for each of the following twelve factors. A comparison of the findings will start a debate about what is really happening within the service. Wherever the service is on this continuum provides room for praise as staff and users have already taken a first brave step: they have become aware of their position. They can begin to ask what needs be done. What small, achievable step will move the service half a point, or even a whole point, in the direction of developing a ‘Recovery Approach’?

The process starts and the features include the following movements in the direction of recovery:

Monitoring Mental Illness	to	Increasing and Broadening Mental Health
Low Expectations	to	High Expectations
Managed care	to	Self Management
Social Isolation	to	Social Inclusion
User Involvement	to	User Partnerships/Alliances
Project staff	to	People Navigators
Dependence	to	Interdependence
Service Led	to	Aims Led
Safety/security	to	‘Feel the fear and do it anyway’
Service for Life	to	Moving on
Problem Focused	to	Solution-Focused
Building-based	to	Community inclusion

4. RECOVERY AS A PROCESS

Many people want a ‘blueprint’ for recovery, so that they get on and do it. But it is not that simple. Everyone is unique and has to be recognised as different, but valued, for who they are and what they bring. The path to recovery is specific for each person. It is their path. For NSF to respond, we need to invest in the following:

Belief

Recovery is founded on the belief that everyone can recover. There can be no more talk, or telling silences, about “hopeless cases”. Individuals starting on a journey of recovery must believe it is possible. Staff, carers and services have to carry a similar belief. They will only support people if they believe recovery is possible for everyone. Staff can be important ‘holders of hope’. Belief, commitment and conviction are infectious.

Self-assessment

Entering the psychiatric system is to be subjected to a battery of assessments. Professionals can use assessments to decide the best way to be in control. Professional assessments can also be about ‘gate-keeping’. The clinical purpose may be about reducing symptoms and ensuring a safety. It is hard to see how the person using the service can be ‘fully involved’ in this process. We know from much anecdotal evidence across the country that many people using services hear about their care plan only at the *end* of the professional assessment process. Even where people are more involved, the expectations of the professionals are often so low that the individual is unable to contribute what they really hope for or even dream about.

There are a number of tools that assist people to make their own assessment. The CUES²⁴ tool, produced by NSF, can be good starting point. Other tools can be used such as the Avon Measure²⁵, which can be accessed through MIND, and WRAP²⁶.

Self-assessment can be a frightening and disconcerting process. It may be the first recognition that things need to change and that the responsibility *and possibilities* for change lie within the user, not with other people or systems. It can involve much pain and difficulty, because personal denial is at work in not accepting that there is a problem. It is also about moving from anger at the system to using the system.

It is often useful to have someone to act as a guide during self-assessment. Some of the tools can be used without support, but someone who can act as a guide is often important. These tools can also be used to prepare for, but ultimately take a central place in, care planning meetings. Checklists can also be useful. It is important, if someone is supporting or guiding the process, that it is ‘holistic’. It is the recognition that mental distress is a response to the person’s whole environment.

Recommendation 1:

²⁴ CUES (Carers’ and Users’ Expectations of Services) was developed by a partnership that included Royal College of Psychiatry, Royal College of Nursing, NSF, and University of East Anglia. There is a Carer and a User Version. Copies can be obtained through NSF Publications Department.

²⁵ The Avon Measure was produced in a collaborative venture involving the Health Authority, NHS Trusts, Voluntary Sector representatives, users and carers in the former County of Avon. Copies can be obtained through Mind Publications.

²⁶ For details of WRAP contact University of Central England, Centre for Mental Health Policy.

All NSF services should have CUES and other self-assessment tools available for users.

Recovery is a unique and individual journey

It is crucial that the journey is owned by the individual and not by others. People may not be ready to start on a journey. They may not be clear about the destination. They may be fearful about the journey itself. A lot of work may need to be done to prepare the way. It may be necessary to explore the dreams and aspirations that can be re-ignited. Two things are important at this stage:

a. Listening skills

Staff must be able to listen and get below the level of obtaining facts. Listening is a difficult skill to acquire, especially if we have no immediate solutions to offer and we have low expectations for change. We need to believe there is an answer through our conviction in recovery. We need to learn to listen at that deeper level where the person has found a way to express what they mean.

A course is to be developed to bring together a range of basic skills that assist with recovery. This will incorporate some of the skills included in the pilot 'Solution Focused Coaching' course.

Recommendation 2:

NSF should provide 'People-centred, Solution-focused, Listening Skills' training that is available to all teams in time, with some elements built into the induction of new staff at an early stage.

b. Creating a culture of interdependence

Services cannot focus only on being safe and comfortable if they have ambitions to offer more than maintenance. There has to be an understanding that people will take risks, recover, move-on, and also possibly return. The Mental Health Team in Gloucester carried out an analysis recently of the needs of their caseload across the entire city using CUES and the Camberwell Assessment Tool. The findings from both approaches indicated that the greatest unmet need for people was to have close friends. Services need to find out what they can do about this fundamental, expressed, but unmet need. People using services are often socially isolated from family and friends. They develop relationships within services, but it is important for services to develop skills to work with families and/or friends and neighbours, so that building and sustaining friendships can become a reality for people using services. In creating links with organisations and interests outside the mental health services, people may choose to build (or rebuild) social networks that add meaning to their life, but also enrich their communities.

Developing Self-Awareness, Self-Confidence, Self-Esteem and Self-Acceptance

The path to recovery cannot be started until the person has already begun to have a sense of themselves as having rights and responsibilities in society. Services need to find ways to nourish and encourage the skills, experiences and qualities specific to every individual

that makes them feel good about themselves. Self-assessment may be the start of self-awareness. What opportunities are there for people to try things out, to become involved, and to begin to build their confidence and self-esteem? Self-acceptance comes from an emerging sense of confidence and esteem. Services can play an important role in accepting the experiences of the people who use the service. They can help make sense of what does always seem to make sense.

The Solution Focused Coaching training showed us the power of ‘complimenting’ as a tool. It can very quickly help to build positive self-belief. For example, recognising the achievement, despite everything, of having got to the service may make a huge difference to someone who has really struggled to get there. Ordinarily, this goes unrecognised.

Some people have managed to hold on to their self-belief until they find themselves in services where the culture provides little hope. It is our responsibility to ensure that an approach to NSF help does not further disable the person. In some instances, people may be helped by diverting them away from full involvement with services. It can sometimes be better to build on the skills and resources they already have.

Developing staff roles as ‘People Navigators’ and ‘Holders of Hope’

Surveys in the old hospitals to identify the patients’ preference for members of staff almost always identified the ‘ward cleaner’ or a porter as the people patients found to be most helpful and supportive. In services today it is interesting to observe how different staff will try to engage with people using the service. There is a sense that staff are there to be responsible, and to know how to cope. There is the sense that people using services feel safe because the staff are able to carry that safety. Staff structures encourage staff to take responsibility and demonstrate competence in taking control. Paradoxically, members often feel more comfortable with staff who, like them, have little authority.

People Navigators are people ‘chosen’ by the person to assist them with their journey. They may include friends, family members, health or social services professionals or NSF staff. The challenge for staff is to be able to support people with their journey or to support others who have been given that responsibility.

Recommendation 3:

NSF should devise training packages to enable staff to work as ‘navigators’ and guides.

Recovery and Self-management Techniques

Self-management encompasses those things that enable people to take greater control of their symptoms. A number of tools have been developed, but there is mixed evidence to date about the value and take up of these tools. There is some evidence to suggest that people have always found ways of to make their symptom more bearable.

Work with some people in Oxfordshire who had been diagnosed with schizophrenia over thirty years ago showed that, despite the fact that they were not given information to help them understand their diagnosis, they had found ways of managing their symptoms. One

man walked a great deal, after discovering for himself that voices did not disturb him when he was walking. One woman found her voice hearing, not necessarily distressing, but definitely an irritant. She decided that she did not want to hear voices. She negotiated with her psychiatrist to be able to self-manage her medication, so that she could suppress the voices. Discussion with people who attend Hearing Voices Groups have led to a greater understanding about how people have found it more useful to develop ways of managing their voices. Some voices are distressing and may need to be controlled. Other voices may be helpful and supportive, and even support a person's recovery.

The Manic-Depressive Fellowship have developed a useful self-management programme. The programme has been well received, but there is a long waiting list of people who want to use the programme.

NSF has recently recruited David Martyn, as Self-Management Project Manager, to research the applicability self-management approaches for people with a diagnosis of schizophrenia. The project will work with people who use services directly and also analyse research and evidence form the experience of other self-management programmes.

Recommendation 4:

NSF should work on a number of flexible tools that can assist in the self-management of 'Early warning signs', 'Medication', 'Voice hearing', 'Risk' and 'Crisis' management'.

Recommendation 5:

NSF should explore with the Hearing Voices Network the possibility of making an alliance to develop Hearing Voices Groups in NSF services.

Recommendation 6:

NSF services should develop relationships with local pharmacists who may be prepared to advise on the self-management of medication.

Recommendation 7:

NSF services should have available copies of a range of current self-management publications, including: 'Victim to Victor', 'Working with Voices', 'Working with Self Harm', and 'Working to Recovery' (Handsell Publications).

Fear of Change

All change is accompanied by doubt, uncertainty and fear. No matter how desirable the outcome, fear can derail the process. Fears can be very strong, even overwhelming at times, especially for those who have been using mental health services for a long time. Navigators have a role in supporting the person in managing these fears. We need to recognise the validity of these fears and the pain that goes with them. This can be difficult for staff if the previous emphasis has been given to avoiding pain, hurt, anger and distress. We need to learn to be able to support people, if that is what they want us to do.

There is danger in seeing the journey as a straight and unbroken road moving in one direction. This is far from the case. The fear of change can be strong at the beginning of the journey, but then equally strong when the person has significantly recovered. It is a fluctuating process with periods of learning, growth, as well as other periods of setbacks.

Recommendation 8:

Training should be developed for staff so they may become skilled in working with people experiencing fear.

How services can provide opportunities for people to access objective information about the management of their mental distress so that they can make informed choices

Real and informed choices are built on information. We must become well informed about the different understandings of mental distress, and the way in which different explanations can lead to different solutions. People using our services have the right to access to the best information currently available. Services need to provide access to books, tapes, videos, as well as access to the internet. These are important tools for accessing information. Giving people a choice is consequent on this. Choice is a political and therapeutic consequence of the Recovery Approach. People are the natural experts in their own life journey. Their mental health is an important part of this.

Recommendation 9:

Information should be developed in an accessible form and made available to people using NSF services. Information should cover mental health and illness, a range of treatments, housing, employment, benefits, etc. This needs to include current local information.

Recommendation 10:

NSF's information strategy should include the aim to provide access to the Internet to service users.

Recommendation 11:

Staff training should encourage an understanding of mental distress from different perspectives.

Recommendation 12:

Understanding mental illness in Staff Induction Training should be redesigned to move towards understandings of mental distress.

Small, achievable steps

“Recovery is a process, not something you can do and finish, and even such small steps may be very important to some. The key is that in each case, however small the step, *the individual is actively deciding to take it*, and this is what distinguishes a move towards recovery from simply receiving services.”²⁷

One of the biggest mistakes is encouraging people to run before they learn to walk. Inevitably some people will do this anyway. Some will even succeed. For most people it

²⁷ Cliff Prior. “NSF and the Vision of Recovery”. Internal NSF Document, November 1999.

is important to encourage small and achievable steps. The important thing is that the person decides on the steps that are meaningful to them. In the work on Solution Focused Coaching, we found that ‘scaling questions’ were a useful way of supporting people in the process of making their decision to make that first step.

Help from others

The process of recovery may be an individual one, but *everyone* that we spoke to acknowledged the help of key people. Services are an access point to a resource of key people. Staff as people navigators may play this role directly, or they might help create the circumstances where other people can take on this role. We know much good work done in projects has been done not only by staff but by other people who use the service. This ‘self-help’ approach to recovery may grow out of informal friendships, or it can be more structured. We can envisage NSF employing people who have a ‘lived experience’ of recovery from mental distress because of their ability to foster these relationships.

A socially inclusive approach would support people in situations where they would be able to find and sustain support in their own communities. This might involve working with the people closest to them, the people where they live, the people at work, or supporting them with relationships based on their particular interests. The family for many people is the key. Services need to begin to include families, where appropriate, in helping individuals to find pathways to recovery.

A Recovery Plan

Part of supporting people towards recovery can be to support them in drawing up their own ‘recovery plan’. Plans might start with identifying small steps, or they might include the ‘dreams’ or aspirations the individual holds for themselves, and then work back to the small, achievable steps they are able to take. As the plan begins to set down those steps, it will identify the people who are already there to help, it will identify resources and tools that might assist on the way, and it will set down how to get help if things go wrong. As with other plans, the recovery plan can be reviewed, revised, and changed at any time. It belongs to the person and it is in their control. What distinguishes a recovery plan from a care plan has been described by Mike Took, “Plans that help the person recover, which is distinct from making arrangements for them to live as best they can with mental illness for the rest of their lives”²⁸.

Recommendation 13:

NSF services should support the development of individual ‘recovery plans’ which are reviewed as the journey unfolds.

Recommendation 14:

NSF services should help people with ‘advance directives’, or advise them where this help can be obtained.

Recommendation 15:

All services should have ‘crisis cards’ available.

²⁸ Mike Took in “Thoughts on Recovery from Severe Mental Illness” October, 2000.

5. THE ENVIRONMENT OF RECOVERY

It would be naïve to think everyone using NSF services is looking for the ‘Recovery Approach’ to be adopted. Services are full of people who all have their own perspective on what they want services to do for them. In many instances they will not want change, they will be familiar with situations where other people make decisions, they will be angry if a new system is foisted upon them. They may not share a sense of ‘hope’: their own experience may not warrant this. In these circumstances the people who can often make a difference are those who have been users of services themselves, but who have been on their own journey of recovery. These ‘role models’ are able to share their ‘lived experience’²⁹, they can offer hope, and they are often able to be challenging in a way that other staff cannot, in a way that helps people who are sceptical to rethink. We must remember that some people seek out voluntary or user-led services because they want to find alternatives to mainstream services. They may be looking for a way to move beyond long-term engagement with the psychiatric system.

The Recovery Approach is one that does not ask, or tell, the individual that they need to change. But it recognises that we ‘have the power to change the environment, including the human interactive environment’. Change can happen in small steps. For example, ensuring there are copies of CUES and other resource material are available helps create such an environment. The effect may be that some people begin to become more aware of themselves in this changing environment. The changes will often go unnoticed at first. Staff may stop running and directing all of the activities, allowing others to take the initiative. People using the service may find themselves complimented for small successes, they may begin to feel better about themselves and think about things they want to change. They may notice more opportunities to try things for themselves.

Alongside this general approach to changing the environment, there will be people actively seeking help with their journey of recovery. For them there is a new and growing culture that supports them with their own journey. It is responsive, knowledgeable and has tools that can help them. It is a holistic approach that is prepared to advocate for people who want to pursue their dreams and aspirations.

6. IMPACT OF THE RECOVERY APPROACH ON SERVICES

6.1. Values

The Recovery Approach changes the value system of services, moving from an ‘illness paradigm’ to a ‘recovery paradigm’. The core belief is that everyone can recover. In this section the impact on services is examined through the set of values which underpin the Recovery Approach.

²⁹ A person’s ‘lived experience’ of ‘mental distress’ or ‘recovery’ are expressions that are gradually being used more generally in preference to words like ‘user’ or ‘customer’ to highlight the reality of where people are coming from. They give value to the struggles, and to the learning and growth that are a part of these experiences.

The primary objective of services is to enable people to ‘recover’

Services that enable people to recover challenge the ethos that accepts the impact of a maintenance approach to people’s life experiences. For example, if the medication that people take has an adverse effect on their capacity to recover, this is taken up with the clinical team. Service staff act as advocates for people and their recovery journey. Services are designed to ensure that there are many opportunities for people to understand how the Recovery Approach can help them to take control of their lives by providing guidance, information, tools, advocacy and support.

Recommendation 16:

Staff should receive training in ‘self advocacy’ and ‘advocacy’ skills.

How services can provide opportunities for people to reclaim control of their own lives

Many people using mental health services feel they have lost control over their own lives. Services can provide opportunities for people to regain control. This requires opportunities for people to gain positive experiences of exercising choice and power in their own lives. This can be achieved by:

- Creating alliances and partnerships in running services that involve the people using the service being fully involved in how the service is delivered. Breaking down a ‘them and us’ attitude and culture
- Enabling people to be heard on issues that directly impact on their lives such as housing, money and medication
- Involving people in campaigns to achieve change at a local or national level, e.g. the way the benefit system inhibits people from obtaining work opportunities
- Supporting individuals to prepare for Care Conferences and Reviews, so that the agenda relates to their recovery plan
- Supporting people to speak out themselves

Recommendation 17:

Services should move towards an alliance and partnership with service users, in all aspects related to the delivery of the service.

Recommendation 18:

All people using services should receive support to prepare for Case Conferences or Reviews.

Recommendation 19:

Assertiveness training should be available to people using NSF services.

Recommendation 20:

Over the next five years, NSF should set a target of employing 30% of people with a ‘lived experience’ of recovery from mental illness at all levels of the organisation.

How services provide an environment facilitating the development of self-confidence, self-esteem, self-awareness and self-acceptance

Ron Coleman has said that recovery is a journey that involves the development of self-confidence, self-esteem, self-awareness and self-acceptance. Services need to find out how they can support people using their services to develop their own ‘self belief’ system. For some people who use our services it may be necessary to be ‘holders of hope’ for a while, until they can begin to believe they can recover.

People with their own ‘lived experience’ of recovery have an important part to play. It is not just a question of saying, “I’ve done it, so can you”. It is also about illustrating what steps helped that person to recover, some of which might help others to recover. Self-help groups may be the space that supports this work. Self-awareness can start with self-assessment, confidence can be built by taking small, achievable steps. Complimenting people for their achievements can be a very powerful instrument in arousing self-esteem. Validation by others can be the beginning of self-acceptance. The culture of the service needs to help every individual feel better about themselves.

The impact of the physical environment should not be overlooked. A shabby, inaccessible building can indicate to those using it that they are not valued. It speaks volumes to the general public and informs attitudes that can reinforce stigma.

Recommendation 21:

NSF services should work towards creating a culture that rewards, compliments and enables people to find solutions

Recommendation 22:

NSF services should identify people who are prepared to act as ‘role models’ and as ‘people navigators’ for service users.

Recommendation 23:

Training and support should be available to prepare people to act as role models

Recommendation 24:

NSF services should pay attention to the quality of the environment where the service is provided.

6.2. How services can facilitate social inclusion

Inclusive communities are communities valuing difference and diversity. They value everyone for their presence and the gifts they bring. Services can either create a community that is exclusive, one that protects people from society, a safe place, or they can find points of connection that enrich the lives of the people using the service and add to the life of their community. Services working towards social inclusion seek to enable individuals to:

- Support individuals in building a network of people support in the their life
- Recognise and value people for their special gifts
- Break down barriers that make people feel socially excluded within their family and/or community, including stigma, fear and ignorance

Many services have been ‘building-based’ and create safe environments where people are maintained within that closed community. The relationships with staff and other members of the service is valuable, but often creates dependency and amplifies social exclusion. To assist people towards recovery services need to work with people outside the walls of the service.

Many services are working with adult education for example. Many of these initiatives have been developed within services and are exclusive to members of the service. This can be an important first step in enabling people to join with others outside the mental health community. But the next step, either open these courses up to the general public or to relocate into a community setting, is never taken. There needs to be an investment in staff and members’ time in creating the links that will provide people with the opportunity to extend their social networks in relation to health, mental health, culture, spirituality, creativity and leisure pursuits.

The family is often the most important source of support to people. Families need to recover too. It may be an important part of an individual’s recovery to help their relatives to understand how they can best support each other. Services for ‘carers’ and ‘users’ have become separated but there is a need to bring them together as a part of the recovery journey.

We know that there is discrimination in the job market against people with mental distress. All services must consider how they can enable people using the service to work with employers. Employing people who have used services, and involving people who currently use services, in making arrangements, in communicating with other organisations, in meeting people through campaigns, activities and anything that involves the general public, creates opportunities for promoting social inclusion.

We know people of black and other ethnic minority communities are disproportionately represented within statutory mental health services and also under-represented within most of the services NSF provide. This represents three challenges:

- Have these communities already developed more effective recovery strategies so that the need for services has diminished?
- Are there people in these communities, who do not have access to services, who would also benefit from the Recovery Approach, and how do we reach them?

- Can we deliver services with a Recovery Approach that respects the cultural values and need for social inclusion?

As people from black and other ethnic minority groups experience increased discrimination and social exclusion they need to have strong role models to help them to fight back and regain control of their own lives. We need to forge links with the black and other ethnic minority groups if recovery is to be meaningful. We need to learn from black and other ethnic minority groups about their 'lived experience' of mental health services.

Recommendation 25:

NSF services should develop links and opportunities to promote social inclusion with black and other ethnic minority communities.

Recommendation 26:

NSF services should develop skills in working with families.

Recommendation 27:

NSF should apply a strategy that develops services with a Recovery Approach for and with people from black and other ethnic minority communities.

Services provide a holistic approach to helping people achieve their personal goals

The task for all services is to help people towards recovery irrespective of whether the service is a housing service, employment service, day service, outreach service, etc. This means that despite the funding focus and the contractual targets to be met, each service needs to become holistic and recovery orientated. This does not mean that services need to be all things to all people. It means that services should understand their particular roles in the broad scheme and be able to signpost people to the place where they can get what they require. If a resource is not available the service should support that person either with an advocate, or support them to advocate for themselves.

Complimentary therapies provide additional ways in which people can learn to take care and feel good about themselves. We need to increase the potential for people to be able to benefit from a range of health approaches.

Recommendation 28:

NSF should take up opportunities to discuss with local funders the recovery ethos and the development of a holistic approach within specific types of services.

Recommendation 29:

NSF services should take up opportunities to increase the availability of complimentary therapies to service users.

Impact of a Recovery Approach on different types of service

Recovery for every individual involves a unique journey of discovery, growth and challenge. Each service will also respond to the recovery process in a distinct way.

Services can be divided into types: accommodation, employment, day services, residential care, etc. For each there are some distinct factors to be considered. These are basic headings that could be subdivided yet again into further categories. In this section, a number of questions about the adjustments that may be necessary, if services are to develop a recovery-orientated approach, are asked.

6.3. Accommodation

In a review of community care for mental health service users, the Mental Health Task Force commissioned research to find out ‘what users want’³⁰. The largest trawl of individual user views ever undertaken in the UK showed that users most wanted a home. But housing in mental health services is often seen as a therapeutic site, rather than as a home and a fundamental requirement. How many of us would allow our living room, or our bedroom, to become a site for therapeutic intervention? Accommodation risks becoming institutions in the community, with the inherent dangers for users of institutionalisation, isolation and dependency.

Residential Care

Probably the most challenging area to build a recovery ethos is in residential care. Here the people with the greatest disabilities are housed and cared for. Care standards, monitored by a local authority inspection team, put a high value on maintenance and low expectations for recovery. Within the homes there are often large staff teams, working in shifts, on low pay and whose work is more to do with domestic duties than care or rehabilitation. Despite these constraints they do often enable people to become less dependent and some people do move on.

Some questions we need to ask about residential care:

How do we build a partnership culture between residents and staff?

How do we help people who may be isolated from the community in many ways to build up trust again and an outlook onto the community?

How can we begin to value very small steps?

How do we do less and allow people to do more in controlled settings?

How do we do less for the residents and avoid criticism from the inspection units?

³⁰ ‘Creating Community Care’. Report of the Mental Health Foundation Inquiry into Community Care for People with Severe Mental Illness. 1994.

Supported Housing

Some questions that need to be asked within Supported Housing Services:

Can we have 'landlord' duties and also provide support to tenants within their recovery plans?

Can we develop a partnership with tenants to run the service?

What happens when tenants no longer need support?

Can we remove support without having to move the tenants?

How do we provide a holistic service within a housing setting?

Do we need to provide cover 24 hours per day?

How do we create a culture of mutual support when the housing units are dispersed?

How can we support people when they are in crisis?

Does high rent act as a disincentive to recover?

Recommendation 30:

NSF should review how 'supported housing' schemes could be changed to 'floating support' with partner Housing Associations and other funders.

Private Landlord Schemes

The service provided by NSF in respect of schemes that are focused on the support of private tenancies are generally directed towards the needs of the landlords. This imposes a responsibility to the tenants one stage removed. Landlords are in a particularly powerful position in respect of tenants. Tenants that become assertive and demanding of their rights can be seen as difficult and no longer acceptable. Tenants may be reluctant to speak their minds if they are fearful of losing their accommodation. Landlords may be quick to terminate tenancies when tenants become unwell and are more difficult to manage. Conversely landlords may be keen to hold on to other tenants because they do not want to have vacancies.

Some questions that need to be addressed within Private Landlord Schemes:

Can NSF serve two masters, i.e., the landlords and the tenants?

How can we try to support landlords to work with their tenants in a way that facilitates recovery?

Who is best placed to act as an advocate for tenants?

Recommendation 31:

Landlord schemes should provide training for Landlords in the Recovery Approach.

Recommendation 32:

All Landlord schemes should ensure that landlords have access to information about recovery and are able to guide tenants with their recovery plans

6.4. Day services

Day care is widely accepted as an effective means of delivering health and social care. It is more cost-effective than in-patient hospital care³¹, keeping users in touch with their families and connected to the communities in which they live. It is experienced as less stigmatising, disruptive and oppressive³² than in-patient treatment. However, there has been an uneven development of day services. Nationally there has not been a guiding pattern of mental health day service development.

Day services take many different forms. They range from highly structured settings with admission restricted to those who have been allocated a place in a closed group, to open access drop-ins with self-referral. It can be user run or it can be a staff led. It can create opportunities for interdependence and social inclusion or it can be isolated and separated from the community it is located in.

Some questions we need to ask about Day Services:

Is the primary purpose to support people to ‘recover’?

How do we create an environment that supports people to feel more self-confident and builds their self-esteem?

How do we build a service that aims to provide opportunities for people to feel more socially included?

How can staff provide an individually tailored programme to the people who come to the service?

How can we run the service as an alliance and partnership between the people who use the service and the staff?

How do we ensure people who use the service can access a broad range of information to help them in their journey of recovery?

Can we enable people who use the service as a ‘club’ to run it as a self-help resource?

³¹ See for example, Creed et al. (1997). “Cost-effectiveness of day and in-patient psychiatric treatment: results of a randomised controlled trial”. *BMJ*; **314**: 1381-5.

³² Anne Rogers, David Pilgrim & Ron Lacey. “Experiencing Psychiatry: Users’ Views of Services” Macmillan and MIND Publications, 1993.

Can we recruit staff with a ‘lived experience’ of recovery to share their experience with members of the service?

Do Day Services need to be building-based?

To what extent should families, friends and neighbours be encouraged to become involved in NSF day services?

Recommendation 33:

NSF should work with funders to change the emphasis from counting the number of people coming into the service to counting how many people have moved on.

6.5. Employment Services

Individuals with mental health problems face unacceptably high unemployment rates. It is estimated that about 85% are economically inactive³³. Yet despite this high unemployment rate, surveys consistently show that most people with severe mental illness want to work³⁴. People with mental health problems attach a high priority to work and want to work. Since unemployment is closely linked to mental ill health, individuals with mental health problems have *more*, rather than less, need to work. Research indicates the benefits of employment in relation to mental health in a number of key areas, including self-esteem, alleviating psychiatric symptoms and reducing dependency on formal health and social services³⁵.

Recovery brings to employment services a rationale for examining and unpacking the underlying meaning and value of work to the users of the service. It may allow discussion to start on why work is important to users and how this may connect to the larger task of personal development. For users of services work is important because its value includes an increase and maintenance of self-esteem. Employment is connected to increasing social inclusion, interdependence, personal rights and choice.

Some questions for Employment Services:

What role does employment play in the recovery of people?

How can the service develop as an alliance and partnership between the people using the service and the staff?

How can services actively support people into open employment?

³³ Labour Force Survey, winter, 1995-96.

³⁴ Meltzer et al. (1995). “Economic activity and social functioning of adults with psychiatric disorders”. Office of Population Census and Surveys, Surveys of psychiatric morbidity in Great Britain: Report 2.

³⁵ Cook and Razzano. (2000). “Vocational Rehabilitation for persons with schizophrenia; recent research and implications for practice”. Schizophrenia Bulletin; 26:87-103.

Can the service respond holistically to the needs of the people using the service?

What role can the service take up on discrimination issues with local employers?

To what extent does NSF employment practice demonstrate a commitment to people with a 'lived experience' of recovery?

6.6. Outreach Services

Outreach has become an important part of many services, as well as being a service type in its own right. Implicit in the discussions about day services, employment, supported housing and other services is the emphasis on involvement in the community away from the buildings where services may be located. If services are to develop towards social inclusion it becomes vital they 'reach out' into the community. There are many different types of outreach service. Cheltenham NSF has been pioneering an 'assertive outreach' approach with young people and people who have been unable to engage with statutory services for many reasons. Unlike many statutory assertive outreach, this service engages with people on their terms, meets them on their territory, and works towards their agenda. The service has a very practical focus, the need for housing, money, health services etc. is determined by the people who use the service. The individuals are provided with guidance as they work towards their own recovery.

Questions for Outreach Services:

Within the one-to-one working relationship, how do we enable the person using the service to hold the balance of 'power'?

How do we involve the people using the service in partnership to run the service?

How do we enable people to access information services?

How can we involve families, neighbours and friends in developing networks of support?

Do we engage with the community to challenge discrimination and social exclusion?

6.7. Domiciliary Services

The emphasis in domiciliary services can be to do things for people after an assessment has indicated that people need long-term maintenance support. As with Outreach Services it is crucial to ensure that the contact has a recovery focus. The aim of the service should be to enable people to do things for themselves and to take control of their own lives. It does have to be recognised however that some people will need continuing practical help. Some people need to be supported for a time to build trust and confidence before they are able to begin to take back control over parts of their lives again. Staff have a difficult balancing act to perform between 'doing' and 'enabling'.

Some questions for Domiciliary Services:

How can the service perform practical tasks on behalf of their clients, without taking away control, self-determination or eroding opportunities exercising choice?

Can the practical tasks of a domiciliary service be included within a recovery plan?
How can we provide opportunities to build interdependence in the lives of the people who use the service?

How can domiciliary staff best work with families, neighbours and friends to build networks of support?

How do we involve the people using the service in an alliance or partnership to run the service?

6.8. Carers' Support

NSF runs a wide variety of services for carers and these services usually aim to provide information, self-help support, understanding of mental distress and treatment systems, and direct support for carers. It will be important to build an understanding of the Recovery Approach as it might apply to the lives of their relatives but also to provide opportunities for carers to explore the Recovery Approach as a way of them taking back control of their own lives. Living with the mental distress of others is in itself a distressing experience. The message for carers is one of hope for their relatives and hope for themselves.

For some families the history of distress is shared and while the experiences and the understanding of these experiences may be very different there is a general sense that they are dealing with common or shared issues.

Family and friends are extremely important to people who are working towards recovery. The Gloucester Caseload Project³⁶ highlighted how important close relationships are to the many people who use services. The impact on family and friends is often devastating. They continue to love the person who has become unwell, but may find it unbearable to live with their consequent behaviour. Many people talk about changes that occur in their relationships. Family and friends often feel forced to take control because no other option seems to be open to them. Professionals and services often will not talk to the carer and they are left to decide for themselves what to do.

When we talk about recovery and 'family and friends' there are two main areas that have to be considered. There is the role of family members and friends in the recovery journey of their relatives and there is the recovery journey in the lives of the family and friends themselves. One individual we spoke to who is a user of services described how traumatising it was for him when many of his family rejected him because of his mental distress. Some years later he was able to assist his elderly father with tasks that he was

³⁶ Dr. Rob MacPherson et al. "The Gloucester Caseload Project". Severn NHS Trust. Unpublished, 2001.

unable to do. This led to a growing acceptance of him by his family, something that he sees as being an important factor in his ‘recovery journey’. In another situation a carer explained how guilty he felt because he had taken over control of his son’s medication and money. He felt he was not helping his son by doing this. After discussing it in more detail, it transpired that he had only taken over managing his son’s medication and money after his son had asked him if he could help him manage these things more effectively. His son was concerned that he would not remember to take his medication and that he would ‘blow’ all his money ‘down at the pub’ if he had too easy access to it. His son had taken control of a first step on his road to recovery, by asking for support.

Some surveys have indicated that a high percentage of people who experience mental distress have been traumatised in their earlier life³⁷. Sexual abuse has been highlighted as a particular concern. Where these traumas have originated in a family setting it is often difficult to envisage carers and users working together.

Some questions for carers’ support services:

How can we best involve the carers in the recovery journey of their relative?

How can we involve carers who do not share a belief in ‘recovery’?

To what extent do we involve carers in the partnership to run carer support services?

Can we link into training initiatives like the Behavioural Family Therapy scheme in the West Midlands?

To what extent can services support carers in their own recovery journey and also support people in their ‘caring role’?

How can the service ensure that carers are given access to a broad range of information that might help them understand their recovery and the recovery of their relative or friend?

Recommendation 34:

CESP and the carer support services should build recovery principles into educational materials and information for carers.

7. IMPACT OF RECOVERY APPROACH ON STAFF

People navigators

This section looks in detail at what we have learnt during the consultancy about the role of people who help and support people who are making a recovery. We have adopted the term “people navigators” to explain the shift in the role of frontline staff. People who use

³⁷ “We also found that patients diagnosed with schizophrenia were able to relate their experience of hearing voices to stressful and traumatic events in their life history”. Prof. Marius Romme & Sandra Escher. “Making Sense of Voices”. Mind Publications, 2000.

mental health services for their recovery are seen as the pilots, since they are the only one in a position to steer the course of their journey. People who work in mental health services are seen as taking up the role of navigator. They have expertise in making and reading maps, they can help plan the journey and negotiate expected and unexpected difficulties. The 'practitioner style' to be adopted must include listening, engaging, showing respect, being informative and skilled in negotiating.

In the past staff have been recruited from a wide range of backgrounds and skills and they have been expected to develop working practices largely through their own initiative or as part of a local team. In adopting the Recovery Approach the values and culture will change and there is a need to ensure this change is shared by everyone.

The single most important change for staff lies within the value system that underpins the Recovery Approach. Recruitment always recognised the importance of employing staff whose value system corresponds with the culture of the organisation. Skills, knowledge and experience can all be addressed within the service and through training. It is more difficult to change people's values and outlook. It is important for NSF to recruit people with values that are compatible with a 'Recovery Approach'.

Recruiting people who have had a 'lived experience' of recovery from mental distress is critical. Many people who currently work for NSF have made a recovery or are recovering, but we need to recruit people who are also prepared to share their experience with others and to pass on the hope of recovery.

People experience mental distress

To say that 'people' experience mental distress is to state the obvious. The experience of many of the people who use services sometimes seems to contradict this. Two people with very different experiences, using NSF services, described themselves recently as being a 'blob'. One saw herself as the 'blob', while the other experienced other peoples reaction to her as being a 'blob', as being less than human. This is quite an extreme response but it is reflected in the way many people are treated within families, communities and by mental health services. It is as if they do not fully exist as real people. For recovery to work, people using services need to be shown respect and given importance. They need to feel and to be seen as gifted, valued and respected. They need to feel that they have an equal stake in the community in which they live. When a person approaches a service, this is what they are looking for. It is important that we provide it. So they do not experience themselves as being just another 'chronic mental patient' being referred to an NSF service.

Someone who attended a Hearing Voices Group, recently, said he had been asked if he heard voices. When he said that he did the group told him that he was 'lucky', he was 'special'. When asked how this made him feel, he said that it made him feel good. A major role for staff is to help make people feel good about themselves again.

People navigators try to support people in feeling positive about themselves again and understand and value their experiences

People are experts in their own mental health. Recovery is the process whereby the individual regains control over their life.

A major element that takes away control from an individual over their own mental health is not only the experience of mental distress. It is the way professionals can take control of their lives. Too often professionals think they know best. There are times when people are very distressed and clearly need help. It is more often the case that there is no immediate risk to the individual or anyone else, but their views are not listened to and their rights are ignored or violated. The key to the beginning of the recovery process for services is to give back control to individuals. It is their mental health, it is their life. In a fundamental sense they are the experts.

This is a difficult message, for it implies that the responsibility for a person's mental health lies with them. People need to know what their choices are, and they need to be able to choose. They need to feel that no matter how distressed they are, they are in charge. Being in charge may mean handing over some responsibility to others at times. This can still be a step towards recovery.

Insight is an emotive word. To say that someone 'lacks insight' has been used by professionals to dismiss the views of people in distress. To not have insight can be used to mean that the individual does not share the understanding of the professional. Everyone has an understanding of their own situation. There may be different understandings about what is happening and it is helpful to share these differences. To simply assume the professional's understanding is the only one that counts is very short-sighted and it undermines recovery for that person.

A young man who feels that the professionals involved in his care do not understand him often complains about the treatment he receives. When they do not listen to him and dismiss his arguments he gets angry about the treatment he receives. At this point he is dragged off to hospital against his will and forced to take drugs that have horrible side-effects, including impotency. He feels he is being punished for commenting on the way that the professionals do their work. He is said to have no insight. The professionals say he has a paranoid psychosis. He says that they lack insight. Who is right? The situation goes round and round with no progress being made. It can only change when it becomes possible for the professionals to listen to the stated experience of the young man and to respect the fact that he does not like what is happening to him. Change may not come easily, but it then becomes possible.

People navigators are able to listen to the people using services, to understand and validate the person's own understanding, and to help them to take control over their recovery

Taking back control involves the development of self-management strategies.

There is a need to have a range of strategies for self-management. It has already been noted that the starting point for self-management is the individual themselves. Everyone has self-management strategies. The range of potential personal strategies is infinite but their effectiveness boils down to what works for the individual. Staying at home and never going out can be a strategy for dealing with a fear of open spaces, but it leads to a very limited life.

People navigators can help people to understand the strategies they use, to become more self-aware, and to recognise the consequences of these strategies including medication

Taking medication is a strategy. But for many people the consequences of taking the medication, that they are often ‘told’ they ‘must’ take, is as devastating as the distress they are trying to deal with. At the course that was run at Forrester’s for twelve of the people who use day services in Bristol, six people stated that they were seriously concerned about the medication that they had been told they must take. These included uncontrollable and serious weight gain, affects on joints making it more difficult to take exercise, tiredness and an inability to concentrate. It is not acceptable that people should have to live with these side effects, or as one member of the Bristol group pointed out, these are not ‘side effects’ they are the ‘real effects’ of the drugs. There is no doubt some people really do benefit from their medication, and they have been freed from a level of mental distress and enabled to have a fuller life. But medication is only one tool that can help or hinder recovery. Each individual needs to be supported to judge the overall benefits.

The reliance on the use of depot injections by psychiatric teams often undermines the confidence people have to recover. It can also undermine confidence in the team that should be there to support them. The young man mentioned above felt that he was being punished. He could never begin to build his confidence while he was being treated in this way. It is important that the NSF response to self-management of medication is one that supports the person using services to negotiate a regime that assists the person to recover.

Pharmacists, particularly hospital pharmacists, have begun to be asked to comment on the efficacy of the cocktails of medication that some people are being prescribed. Services need to try to identify a local pharmacist who would be prepared to act as an advisor to services.

Recommendation 35:

All frontline staff should have training in medication awareness, its benefits and risks.

People navigators enable people to access resources that will help them manage their disturbing voices

There are many different cultural perspectives associated with hearing voices. They can be seen as a major symptom of a devastating illness, they can be seen as a natural response to stress (Terry Waite ‘heard voices’ when he was held in captivity). Others believe voice hearing as a religious or spiritual experience, and they can be seen as a

special gift. Even if we understand voice hearing to be associated with a severe illness it is concerning that the prognosis for people in many parts of the third world is significantly better than it is in Western societies. An article in the Sunday Times by David Horrobin speculates that voice hearing (in schizophrenia) relates closely to creativity:

“So it seems that the families of schizophrenics exhibit those differences from the rest of us which differentiated modern humans from their boring ancestors. Such families may be enriched by highly artistic or religious individuals, brilliant technologists or scientists, or psychopathic and manipulative political, military or business leaders. It therefore seems to me that it is contributions from the genes that make some of us schizophrenic which made us all human.”³⁸

Hearing Voices Groups are having considerable success in helping people to understand and come to terms with their disturbing voices. More and more, as people are encouraged to talk about their experiences, they are beginning to learn what the voices mean for them. It is important that people are enabled to choose the way they want to manage this experience. For some they will want to suppress the experience, for others they will want to understand it and to learn from it. It is important we help people access resources so they can make their own choices.

Recommendation 36:

All staff should learn to become confident in talking with people about their experience of hearing voices.

Recommendation 37:

Services should develop resources to help people disturbed by voice hearing.

People navigators support people to respond to early warning signs and triggers that may affect their mental health

A number of tools have been developed to assist people with the management of symptoms, triggers and early warning signs. WRAP courses that are based on the work of Mary Ellen Copeland are taught through the University of Central England, Centre for Mental Health Policy, and these are supported by on-going self-help groups.

As a result of obtaining a Beacon Award the IRIS (Initiative to Reduce the Impact of Schizophrenia) Project, have published Early Intervention Guidelines and a Service Framework, including an Early Intervention in Psychosis Toolkit. This sets out very clearly a whole approach, used by the clinical team in North Birmingham, to early intervention³⁹.

³⁸ David Horrobin. “There’s Madness in Mankind’s Method”. *The Sunday Times*. April, 2001.

³⁹ Initiative To Reduce the Impact of Schizophrenia. “Early Intervention In Psychosis - IRIS”. West Midlands Partnership with NSF. Designed and printed by NSF Kaleidoscope, 2001.

Recommendation 38:

NSF should use existing materials within their services to assist people with the development of their own early intervention strategies.

Recommendation 39:

NSF should build on existing materials to develop an approach to early warning signs for people who use NSF services.

People navigators support people to plan for a crisis

The principle of advance directives has been established for some time. NSF's National Advice Service has produced a Performa for an Advance Directive. Mind have run an extensive campaign to encourage people to carry Crisis Cards.

There are difficulties about the legal status of these directives and Crisis Cards. This may have discouraged their development. If people have negotiated with their community mental health team about the response that they would hope to get in a crisis, this will often have a much greater impact. Services can support people to negotiate with their clinical teams to plan for how the management of a crisis in their lives can be part of their recovery plan.

Recommendation 40:

All NSF services should have support with Crisis Management and Advance Directives available to them.

People Navigators assist people to manage the things that make them vulnerable

Work has been done in NSF in South and South-West Directorate Housing Forum on the self-management of risk. This looked at risk as the primary concern of the person using the service, rather than the sole responsibility of the service. An NSF report⁴⁰ was written, following research in Cheltenham that surveyed the experiences of people with a history of being excluded from mental health services. Many of these people had been categorised as having a 'personality disorder', because of their behaviour. The report concluded that this group were more often the victims of violence than the perpetrators of it. Many of these people lived in flats where the local council also accommodated homeless people, young offenders and drug addicts. People with the mental health problems were preyed on for money, victimised and abused. In these circumstances it was not surprising that they seemed disturbed and their behaviour unpredictable. One person living in a ground floor flat was terrorised by local children. When he needed help the most from a day service he was banned and classified as having a personality disorder. When he moved to a first floor flat he stopped being terrorised and he was allowed back into the day service and restored to a diagnosis of schizophrenia.

Risk Assessment has three stages. In the first stage, it is important, to learn from the person being referred to the service and from others who have known them previously.

⁴⁰ Steve Hennessey. "Living on the Edge". Unpublished report commissioned by Cheltenham Locality Planning Team from NSF, 1995.

This can be particularly important in housing services when a history of arson, for example, might need to be carefully addressed. This leads on to the second stage that involves supporting the individual to develop a self-management plan to address the risks that are real for this person. The third stage involves working with the individual to take responsibility for planning how a situation, that appears to be getting out of control, should be managed with the support of others. This approach to Risk Assessment and Risk Management gives the responsibility to the person using the service at all times. It is part of their overall recovery plan.

Recommendation 41:

NSF services should develop an approach to risk assessment and risk management that always involves service users taking responsibility and control of the issues affecting their own safety and the safety of others.

People navigators help people to recognise their own giftedness and encourage them to grow in self-awareness as unique and valued individuals

Recovery is a process of growth involving the transformation of ‘disability’ into ‘giftedness’. The people who are recovering speak about how they have been able to learn from the distress that they have experienced. They have been able to grow. The ‘gift’ may be an understanding of being able learn and to grow from fearful and distressing experiences. The ‘gift’ can also be the experience of being different and learning to appreciate that difference. Some individuals have come to regard their disability as part of their humanity, their gift, because it singles them out and makes them who they are. There is a wonderful book of hope and ‘giftedness’ written by many people who have come through a process of ‘recovery’ in their lives. It is called, “A Gift of Stories” by Julie Leibrich, published by The University of Otago Press.

It may be a difficult thing to do, but NSF services and staff need to be permanently positive about the people who use the services⁴¹. Not patronising and ‘nice’, but positive about the people as people; to be positive about the qualities they have as people, and the contribution that they can make. There is a real challenge to break down ‘them’ and ‘us’ attitudes. It can build the alliances and partnerships that value people equally. The status of being a manager or a worker can get in the way, in the same way that a closed office can make people feel that they are second class. Opening offices, developing roles as navigators, create the opportunities for people to recognise and develop their ‘gifts’.

Recommendation 42:

NSF Offices should develop open door policies and practices.

Recommendation 43:

NSF services should have written material such as “A Gift of Stories” and images that give inspiring messages to people using the service.

⁴¹ It has been interesting to note that when the word ‘giftedness’ has been presented to professionals they almost invariably do not like it, whereas the reverse has been true when the word has been presented to the people who use services.

People navigators assist people to explore the potential to build a network of support involving family, friends and people in the local community

Recovery involves supporting people to re-build networks of support including family and friends. Many services have in the past focused on the group who are the identified 'clients', who have been referred to the service. It could be said that they have developed structures designed to keep most people out. If we are to build a framework for social inclusion this will involve going out to people in their communities and also enabling the community to come into services. This will involve developing community work skills and changing work practices. It requires services to address how to include family, friends and others in the recovery process.

Services will need to become integrated into their communities and move beyond being 'an institution in the community'. If this is to be done successfully it involves reassuring people that their world is not to be invaded or taken over. It involves discussion in services about how social inclusion can be achieved. It needs to be achieved one step at a time.

The most important supports for many people lie within the family and/or close friends. Services will need to accept the challenge of including relatives, friends and neighbours so that they can also learn about how to support recovery.

People navigators recognise the challenges within recovery and are there to support people at times of difficulty

Recovery is a process of change and fear of change is part of that process. Every step towards recovery can and will involve doubts and fears. Individuals will need reassurance. If it was easy they would have done it already. 'Feel the fear and do it anyway' is a part of what services aiming for recovery are about. People who have been there before and have succeeded are a real asset at times like this. They can be more approachable because they are more vulnerable. They can help and support, drawing from their own experience in ways that people who have not had the same experience cannot.

It is important to acknowledge the validity and presence of these feelings. We have all been in change processes, we can share how we have felt when we were powerless, and in the hands of others. People can be given information that will help them to take the next step, they can practice skills that will be necessary, and they can try it out in role-play. It is possible to reassure people that we will still be there if things do not go according to plan. It is important to recognise that the further a person travels on the road to recovery, the further they can fall back. Anxieties and fears may be at their greatest the closer a person gets to their goal. Guiding and navigating does not stop after the first few steps. People need to be sure that they can return to services when they need them.

Recommendation 44:

All referral systems should be reviewed to assess if it is possible for people to easily return to services if they require them again.

People Navigators recognise the value of making small steps, and taking one step at a time

Everyone who begins to take back control over their lives, by however small a step, is on a pathway to 'recovery'. The importance of small steps has been mentioned all the way through this account. In a residential service the plan was to get Fred out from hiding under his jumper, onto a bus and into town. Fred was not involved in this plan. He had no desire to go anywhere and it is not surprising that many years later Fred is still under his jumper. Small steps for Fred might mean he spends slightly less time under his jumper, but the real challenge is how to get Fred to engage in the recovery process. Fred, like many of the people who are live in residential care homes, has been very disabled by his experiences. He is almost uncommunicative and gets irritable if questioned too closely. How do we make recovery relevant to him and many other people in a similar position? We can introduce people who have taken a journey of recovery, we can compliment people for their achievements, we can be positive about the future, we can provide hope.

Some real successes have been recorded by people who have researched the lives of people who have withdrawn to this extent. They have found out about music they like, people who are or were important to them, ambitions they may have had in the past. They have tried to find out what might make a difference for this person, and who they might relate to. In one instance it was known that a person liked men with ear-rings and certain types of music and this made a difference to helping the person begin to think about a first small step. This is time-consuming work, there may be many cul-de-sacs, but the rewards are huge, when a person who has been damaged by their experiences, begins to actively trust people again.

People navigators support people in being able to make the same choices that anyone else would expect to be able to make

People who experience mental distress have the same rights and responsibilities as other members of society. This is clearly not happening currently. Stories about people with severe mental illness are often transmitted using words such as 'psycho' or 'nutter'. No other socially excluded group has to endure such unregulated stigmatisation. It is vital that services treat people as full members of society and with the same rights as other members of society. Rights bring responsibilities. Recovery is not an easy, idealistic option. It is a hard and difficult option for people who use services but also for the people who provide services.

People have the right to say that they do not want to recover, they would prefer to stay as they are. They do have the right to choose. Services must decide to what extent they can invest resources into situations that are unchanging. A service that works as a club at week-ends, where people come to chat and to be looked after, may be supported in the future as a self-help group rather than have staff members cooking meals. If services are to take up the recovery agenda, staff time becomes even more precious than it has been in the past. It will not be possible to give people the individual attention to help guide

recovery plans and at the same time deliver a service where the members want everything arranged and done for them.

Recommendation 45:

NSF services should review and assess whether there are opportunities for the members to take control of part of the service within a supported self-help framework.

8. IMPLICATIONS OF RECOVERY APPROACH FOR OTHER FUNCTIONAL AREAS WITHIN NSF

The bulk of this report has been addressed at the implications of the Recovery Approach within the Operations Directorate, but is also important consider how the approach will also impact on other areas.

8.1. Human Resources

The Human Resources Directorate has a key role in the development of the recovery culture in NSF. With responsibility for staff and staff development they have a major influence on how staff join the organisation, take up their contract of employment, learn about NSF through induction and ongoing training, and through their involvement in the range of issues that affect staff during their employment.

Some questions for Human Resources:

On Recruitment and Selection

How can we advertise in a way that attracts people with values that reflect a Recovery Approach?

Can we advertise specifically for people who have a ‘lived experience’ of recovery from mental distress?

Can we build into job descriptions, and person specifications, ‘people navigator’/‘holders of hope’ skills?

Can we identify the specific skills, that people with a ‘lived experience’ of recovery from mental distress have, that can be included within a personal specification?

How do we ensure that interview questions help us to identify people with recovery values?

Can we ask people with a ‘lived experience’ of recovery from mental distress to talk at interview about their experiences?

Can we provide a structure for selection, that reflects the need to ask people about their experiences, which is still respectful to them?

On Induction

How do we build into the induction process the hope and excitement of the Recovery Approach at a time when we are moving forward slowly and at different rates across the country?

How do we ensure that new services build the Recovery Approach into their service from the start?

Do we need to consider extending the induction package to include solution focused listening skills, advocacy skills, a broader understanding of mental distress, and people navigator skills?

On Training

How do we ensure that services have a range of skills available to support people on their recovery journey –solution focused listening skills, advocacy skills, self management skills, data base skills, social inclusion skills, family work skills, etc?

Can we involve staff in external training so that we are part of that broader Recovery Movement and can learn from and add to the collective experience that informs good practice?

A number of initiatives are available:

-Ron Coleman has developed a number of training initiatives including the Victim to Victim series.

-Keith Copeland and Eric Davies run a Thorn Course and a range of other options that encompass a Recovery Approach.

-Piers Allott at University of Central England (UCE) in Birmingham runs a number of WRAP courses that have a specific recovery focus.

-Increasingly recovery conferences are drawing in people who have considerable expertise in recovery from various parts of the world.

On a framework for Staff Support

How can we ensure staff are supported to empower the people who use the service?

How do we ensure staff are supported when the people using the service take risks and these do not work out?

How do we ensure supervision and appraisal systems provide support for staff to develop and practice recovery skills?

Can we build a culture of peer support within services where staff are encouraged to seek and receive support from colleagues?

Can we build a staff culture of support that ensures that people are not discriminated against, or socially excluded, due to their mental health, colour, ethnic group, disability or age?

Recommendation 46:

Human Resources, in conjunction with Service Development, should make bids to draw additional funding in to provide additional training to promote the development of a Recovery Approach.

8.2. Public Affairs

Over the last few years we have seen the importance of the Public Affairs Directorate grow within NSF. It is responsible for the developments around NSF's Corporate Image, Campaigns, Fund Raising, Information and The National Advice Service, Policy Development, and Services to Members. Public Affairs projects the image of the organisation outwards and in so doing also holds up a mirror to what is happening internally. Considerable energy has been generated over the proposed changes to the corporate image, the proposed name change and the values and beliefs that are part of this. As has been said above 'recovery' is not an add on, it needs to be part of those values and beliefs that drive the culture of the organisation forward. Insofar as recovery is a 'radical' departure from a maintenance approach to service delivery, recovery implies a 'radical' change to the corporate message given out by NSF.

Some questions in relation to:

Corporate Image

How can we ensure that the statements about mental distress express this broader understanding of people's experience?

How do we reconcile the aspirations of 'hope' within the lives of people who use services with the concerns of family members?

How do we reflect within the Trustees the view that people who use services are the 'experts' in mental distress?

How do we focus on the recovery of people with an experience of mental distress and their families and at the same time challenge social exclusion?

Research, Campaigns, Fund Raising, and Conference

How will Research and Campaigning be built into local initiatives to enable people within services to develop self-confidence and self-esteem?

How can Research help us to best identify proven models of best practice?

How can Research and Campaigns contribute to building a culture of recovery in NSF?

How can the fundraising build on the recovery initiative to identify funding that can be brought into directly develop the Recovery Approach?

How can we best develop a programme of conferences that encourage funders and others to join with us in developing a recovery culture?

Recommendation 47:

Research, Campaigns and Fundraising should develop a stronger local profile and provide opportunities for people using services to become involved.

NSF's National Advice Service

How can we build on the work of the National Advice Service to develop skills in advocacy, advice and information across the services?

Can the information data-base, developed by the National Advice Service, be made more accessible to all services?

Can we develop intranet and internet skills to draw on the information data bases that are available?

Membership

How can we make the message of recovery attractive to our long-standing members?

How can we use the developments in the Recovery Approach to build NSF membership?

How can members become more actively involved in learning about, promoting and supporting the development of the Recovery Approach?

Can membership be a force in combating social exclusion?

8.3. Service Development

Service Development is a small but important directorate within NSF. It will have the lead in terms of the further development of the 'recovery' approach. If the Recovery Approach is to be embedded within NSF then all new services will need to be developed in a way that is consistent to recovery values and principles. The challenge will be to persuade 'sceptic funders' to invest in recovery, to convince them that recovery is about 'added value'. We also need to be clear that we are no longer prepared to develop new services that only provide a 'maintenance' approach. Contacts with funders over the course of the last six months suggest that funders quickly respond to the ideas and principals of recovery. They like the involvement of the people who use services and

carers, working to a plan, the idea that people will ‘recover’ and ‘move-on’. They are unfamiliar with the individual being in control, taking responsibility, and having the right to choose. They may be uncomfortable with ‘handing over’ professional and statutory authority. They may not understand the meaning of partnerships and alliances but if we involve the people themselves in the negotiations we have the potential move ‘mountains’.

The Development Directorate also has the responsibility for the further Quality Standards and ensuring auditing of these standards for service delivery. Recovery brings a new set of values and principals that need to run through Quality Standards. Some recommendations make specific reference to tools that should be available in all services, these need to be reflected within Quality Standards.

Some questions for Service Development:

Can every new service have a recovery value system built in from the start?

How can we involve people with a ‘lived experience’ of recovery from mental distress more actively within the development of new services?

How can people with a ‘lived experience’ of recovery be involved in the audit and review of Quality Standards?

Can the self-management initiative be run by people with a ‘lived experience’ of recovery from mental distress?

Can the self-management initiative develop tools that can be used within all NSF services?

Recommendation 48:

Quality Standards should be reviewed and updated to include recovery principals and to involve people with a “lived experience” of recovery.

8.4. Finance

NSF is almost entirely dependent on obtaining contracts through funding organisations in the statutory health and social services sector. It has never been ‘free’ to develop services independently. Embedding recovery within NSF will for the first time indicate to funders that we are ‘in business’ to promote an approach to service delivery that gives people who use services the power to direct their own recovery and that this may challenge the way they, as funders, commission services. This will present problems and opportunities. It will be important for NSF to build on the opportunities that arise because of this commitment to the Recovery Approach and to recognise that we may have to give up some services and we might lose others.

Recovery demands a principled approach to development. An approach that is based on values, and that is concerned about the quality of the service before contractual and

pecuniary opportunities. The Finance Department will need to be well versed in recovery so that they can work alongside operational and development staff to build on the opportunities that become available.

Some questions for the Finance Directorate:

How can we best prepare to withdraw from services that cannot be adapted to a Recovery Approach?

What part can finance play in working with funders to demonstrate the added value and best value principles within recovery?

8.5. Voices

Voices are not strictly within NSF but have an affiliation and link through the Board of Trustees. They represent an important constituency in terms of the 'service user' voice within NSF, and as a National Forum in their own right. There is considerable interest within Voices in relation to the Recovery Approach. They have had Ron Coleman as a speaker at their last National Conference, and they are considering holding a 'Recovery Conference' this year. Voices were represented on the interview panel to appoint the member staff to take the Self-Management Project forward.

There is a real opportunity within NSF to involve this affiliated user group fully in the future development and auditing of the Recovery Approach.

Some questions we might ask about NSF's relationship to Voices:

How can Voices be involved in the development of the Recovery Approach?

Should Voices have a stronger representation within NSF?

Could Voices become directly involved in the development of tools for recovery?

Can Voices play an active role within the pilot learning sites?

Can Voices take on a role to monitor the development of recovery within NSF?

Recommendation 49:

The involvement of Voices should be built into the development and auditing of NSF's Recovery Approach

9. NEXT STEPS

There are many challenges within recovery. It would be a mistake to think that change will happen overnight. NSF is a large organisation with about 350 services and 1,600 staff. It will take time and effort to fully develop a recovery culture across the whole

organisation. The principles of Recovery Approach are not totally alien to most people who are involved within the organisation. Many people will take to these ideas with relish and enthusiasm. We are also not starting from the beginning. Most services have already moved beyond a maintenance approach. Many are actively looking to progress further.

The way forward can be likened to a ‘recovery process’ for NSF itself. We need to carry out a ‘self assessment’ and to decide what we need to do, in the context of our goals and recognise that each service will have its own journey to make. Understanding where we are and where we want to get to we can build confidence and pride in our achievements. We must recognise we will need allies who can support us with our journey. We need to value these allies and supporters and be generous in supporting their efforts in return. We need to develop tools and resources that will enable us to progress. We must recognise some people will be very fearful of this change and they will need our collective support to make progress. We need to move forward in small, achievable steps. These are our suggestions for moving forward.

9.1. The Initial Plan

Continue to build a recovery culture within NSF as a whole

We want to build on the energy and enthusiasm that has been generated during the initial year of discussing the Recovery Approach. The primary aim will be to encourage every service and directorate to continue to explore and develop ideas and approaches to recovery. There is much that can be done straight away. Services can obtain copies of CUES, and Victim to Victor Self Management plans and other tools that are available. They can begin a dialogue with the people using services to create a partnership/alliance. They can continue to discuss how recovery can be implemented within the service. Conferences, training initiatives can be followed up. Advance Directive formats and Crisis cards can be made available in all services.

Develop a number of eight recovery pilot learning sites

About eight sites representing a geographic spread across England and Wales and a broad spectrum of different types of service will be selected as Beacons of recovery. They will receive additional resources to help them move towards a Recovery Approach and in turn they will help to develop tools and disseminate information across the NSF.

The process for services to become identified as a recovery learning site is:

- Expression of interest
- Evaluation of the values of service against recovery values
- Evaluation of enthusiasm amongst staff and members

- Evaluation of the capacity for the service to work with mental health colleagues in their local area to promote recovery
- A spread of sites across England, Wales and Northern Ireland
- Representation of different types of service
- A written proposal from staff and members setting out how they plan to move forward.
- Decision to be made in conjunction with Directors of Operations in England and the Directors for Cymru and Northern Ireland.

Establish a National Recovery Approach Steering Group

Build recovery ethos and approach into all new services

New Services to be developed with a recovery ethos. The emphasis will be to try to get it right first time.

Hold a ‘Champions of Recovery’ Conference within this financial year

A ‘Champions of Recovery’ Conference will be planned for people who have a ‘lived experience’ of recovery and who are involved within NSF as staff, volunteers, people using services, to celebrate their achievements, build on their energy and enthusiasm for recovery, and to give them a major voice in the development of recovery.

Develop Self-Management Tools to assist with recovery

The Self-Management Project will feed into the resources that are already available. It is anticipated that this project will work closely with the Beacon sites to test out the tools that are to be developed.

Review recruitment, selection and corporate induction in the light of recovery

Recovery will be built into the recruitment, selection and induction processes. A new two day Induction Course is currently being developed and recovery is already being built into this.

Develop a ‘Solutions and Recovery’ Training to be delivered to NSF teams

A training course will be developed out of the Solution Focused Coaching Course to help teams build on their existing skills and this will be tested within the Beacon sites.

NSF to work with others in taking recovery forward

NSF will tie into Recovery Networks within the UK. NSF will cultivate the allies that are already there, and build on these. NSF will involve allies in the planning, development and monitoring of the Recovery Approach.

Quality Standards to be reviewed in the light of recovery

Information to be disseminated across NSF services

To make available to all services an Information Database, including information developed by the National Advice Service.

9.2. Longer Term Plans

- To implement new Quality Standards across NSF
- To develop a monitoring tool, involving people with a 'lived experience' of recovery, that can audit recovery practice within NSF services
- To revise policies to reflect Recovery Approach
- To have developed a range of tools available within all services
- To build recovery values into staff and volunteer supervision
- To have developed training and personal development plans linked to the Recovery Approach
- To build into staff/team profiles community work, social inclusion and family work skills
- To develop pathways for people to be employed because of their 'lived experience' of recovery to act as 'role models' and 'people navigators'.

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