

Recovery So Far – 13th July 2000

The last few months have seen a gradual build up of interest in terms of the development of a Recovery Model within NSF culture. It is now clearly on the agenda and many groups of staff and members have become engaged in the process.

There is a Zen saying:

“ 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!”

There is a very real sense that having engaging in an exploratory phase in respect of Recovery, there is now no turning back. The asking of the questions posed by Recovery has already begun to shape and change our practice.

This process already imposes responsibilities and highlights dangers that it is important to try and recognize.

- We have a responsibility to respect the values and principles that lie within the ‘Recovery Movement’.
- We need to respect the people who use our services and their aspirations towards ‘recovery’.
- We need to understand respect the aspirations of people who do not use our services who have an understanding of ‘recovery’ in terms of their own lives.
- As a large organisation working in the mental health field we must be careful not to redefine ‘recovery’ to meet our own internal needs.
- We must not define recovery as a restatement of what we already do.

What has been happening so far?

Recovery has been on the agenda of Staff Days within the South/South West Directorate.

Teams of staff have been encouraged to debate with the people using our services what this term recovery means for them and service provision.

We have had presentations and discussions at Operations Managers Meetings on Recovery.

We held a Recovery Day for Operations Managers and Locality Managers within the South/South West Directorate.

A 'Discovery Group' has been set up in Oxfordshire by Dennis Preece bringing together people who use mental health services to explore recovery.

I have begun to have discussions with individual people who already use the term 'recovery' in the management of their mental illness.

Some staff in Worcestershire are engaged in a Self Management pilot scheme developed by Jo Smith, a Psychologist working for the Health Trust.

We have engaged a Trainer in Solution Focused techniques to run a pilot training course to explore how these skills could be used by our staff to enable people to recognize their potential for recovery.

What is Recovery?

We have spent some time exploring definitions and language to do with 'recovery'.

Cliff Prior set out a vision in the paper that he prepared for the Board of Trustees. A key paragraph within that document is as follows:

- "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."

The model is that very individual response to understanding the aspirations of people using our services and supporting them to take the steps that they want to take.

Other important factors within Cliff's paper were to do within the 'inclusiveness' of the model. It does not exclude the medical or social models allowing the individual service user to choose which services enable them to make the progress they want to make. The model should however not seek to entrap people but to free them to be able to have a life of their own.

The model must be relevant to the needs of the people who are most disabled by their mental health problems.

A person who has had reason to use mental health services has defined 'recovery' for her as:

- "I have found that you can live with mental illness and cope as long as you are positive. I recognise that I was older than most people when I had my first psychosis and that it's more difficult for those who become ill around the age of twenty, who

may need help with the basics of coping, including budgeting. However, we must do our best to get on with our lives. You have to do it yourself, welcoming help from other people. It's the only way to have a 'normal' life again, whatever 'normal' may mean to the individual person."

A staff definition generated during the Recovery Day was:

- Recovery allows an individual to discover for themselves a positive quality of life. The process features self-determination, empowerment, agreed support, and focus on the person's strengths; and is actively chosen by the individual.

In Practical Terms What Does Recovery Mean For Our Services?

Paradoxically this model demands even greater skills from our staff. Empowerment is no longer just an ideal to aspire towards it is a day to day reality. Some of the things we have been working on include:

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| Self Management | There are a number of approaches to self Management that have been around for some time. Handouts were given out relating to a pilot research programme develop by Dr. Jo Smith, Psychologist, in Worcestershire. Some NSF staff are involved in the pilot. |
| Recovery Plans | This to a degree is a shift in nomenclature from Care Plan to Recovery Plan. The implication in the shift carries with it the change from a multi-disciplinary agreement to supporting the individual with their plan. |
| Advance Directives | These are not currently consistently available to people who use NSF services. |
| Crisis Cards | As with Advance Directives. |
| Risk Management | The Housing Forum has been working on a risk assessment tool that acknowledges that history is the best predictor of future behaviour, but that a key area of work is to work with the person on their plan to reduce the risk associated with their behaviour. |
| Managing Voices | Ron Coleman and Mike Smith have produced a systematic format for examining and learning to cope with the experience of hearing voices. "Working with Voices – Victim to Victor". |
| New Careers | There is evidence from work done under |

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| | the New Careers programme in USA that where link workers, who have had experience of Mental Illness, are employed as a part of a training initiative to act as advocates for people using a service, the link workers benefit enormously. The service also benefits by this approach. |
| Solution Focused Therapy | The Recovery Model suggests that people using our services in the future will need help with finding solutions to the problems that arise from living with a mental illness. We are currently arranging for a pilot course to be run for NSF staff to see if this is a training that all staff should receive. |
| Cognitive Therapy | It is unlikely that NSF will ever be in a position to train staff as cognitive therapists. However some understanding of cognitive therapy and access to advice would prove valuable. |
| CUES | There are a number of self-assessment tools around. NSF has produced and researched CUES. This tool has the advantage over many of the others in that it can truly be used by the individual on their own, in most situations. |

What does this mean for policy development?

Issues are constantly being raised since this process began and these may have a profound effect on the policies that we have been previously developed.

- Confidentiality and Information Sharing

We have had a very robust policy in respect of confidentiality and information sharing. Recovery has put this policy under some strain. If our staff are supporting people with ‘their’ recovery plan or their interest in ‘self management’, does the individual have the right to insist that the content of what is discussed remains entirely confidential?

- Language of Recovery

The use of words in mental health has been a recurring theme and the issues around labeling and stigma take on a new imperative. It was interesting that the staff at the Recovery Day came out very strongly against terms like ‘service user’ because of the sense of ‘entrapment’. At the service user forum three people using our services felt they needed a label which gave them a sense of identity in relation to using services. They saw

it as similar to being a customer when in a shop, a passenger when on a train, etc. There was a sense that the person using the service has the right to determine how they wanted to be identified.

Conclusion

The Recovery Model is an extremely positive and optimistic Model. It has been noticeable that the people describe themselves as being 'in-recovery' have managed to regard the experience of mental distress as an experience that can be learnt from. It can be the beginning of 'growth and self discovery'. One woman who had been described by a psychiatrist in the most depressing terms considered herself to be better than she ever felt before, more in control of her life than ever before, more productive than ever before. The tragedy was that she almost had to hide this from the psychiatric services supposedly supporting her as they would interpret these thoughts as signs of delusion and illness.

RECOVERY SO FAR 2 - September 2000
(Where has the goose got to now?)

I had just stopped addressing a group of members of a day/employment service. The discussion had been quite lively and there was a considerable amount of interest in the ideas of 'Recovery' despite the fact that most of the members had had long periods in the old psychiatric institutions. I was feeling quite good about the way it had gone down and was hopeful that individual members would want to explore what Recovery might mean for them. At this point I was approached by a member of the group who took me to one side to tell me that the only thing that worked for the members was for, "the staff to tell them what to do". It was one of those moments. Do I argue from my 'superior' knowledge and experience or do I agree that recovery is not an option for people who have had long periods in psychiatric institutions? It was then that I remembered that the Recovery Model is most relevant to individual people. This member was talking about his own 'recovery', his need for direction and support within clearly defined boundaries. This understanding no longer conflicted with the Recovery Model.

A senior manager from one of the statutory services told me of their frustration at having engaged consultants to ask people using services what they want only to be told that they want what they are already getting.

In discussing these two scenarios with a colleague involved in 'recovery' for himself and others he said that the real issue is not about wants or needs, it is about realistic expectations. If a person's expectations are very low then asking them what they want will fall within those expectations. Before we ask people what they want we may well have to help them to raise their expectations.

There will be many pathways to recovery. A Nurse Consultant and a Clinical Psychologist who have been facilitating 'hearing voices' groups for some years in Gloucestershire have been developing tools to help people on their journey to recovery. The pathway has the following steps or stages:

- Asking for help from a supporter.
- Engaging with others and sharing the experience of hearing voices.
- Learning to value these experiences.
- Making sense of these experiences.
- Dealing with the fears associated with changing their view of themselves.
- Developing confidence.
- Becoming their own person again.
- Engaging in activities that are meaningful to them.

Skills and tools have been developed to assist people on this journey. I am exploring ways in which we can learn to incorporate these ideas into the model.

I have had many requests to be involved in Members Days, Staff Days and Conferences. Please continue to involve me in your plans. I am particularly keen to listen to people's own stories of 'recovery'. I would also like to hear from services where you are successfully using crisis cards and/or Advance directives.

Part of my role is to identify allies in other services who will want to work with us to develop and promote the 'recovery model', please let me know of people in your area who I need to talk to.

Derek Turner

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Following the Goose

Despite the fact that I have only just officially started the six months of work on the Recovery Model the goose is out there getting involved in the work of NSF. I have had the opportunity to attend the national Recovery Conference in Birmingham, 'Moving Beyond Maintenance', and to explore ideas with staff, at a Staff Day, members at a Members Day, members of a day service, and funders at a Day Care seminar. It is encouraging that people are keen to engage in the debate and are generally positive about the ideas.

There are some themes that are emerging that will need further thought and discussion.

Consumerism

It is becoming increasingly clear that there is a 'political' dimension to 'recovery'. A growing number of people feel that they have been failed by professional mental health workers. There is a belief that if the people who use services were involved in delivering services things would improve. In developing the model within NSF we will need to develop a strategy for recruiting, training and supporting people who use services because of the particular skills they can bring.

Dependency

It has been interesting to see in discussions with staff and others how there is a clear understanding of the way in which many of our services have fostered dependency. The funders in many ways encourage us to justify our services in ways that

Recovery So Far 4 Giving the Goose a Hand

Working With Solutions

One of the areas that we have been looking at in recent weeks is the development of a set of skills that would assist the NSF staff team to support people with their 'recovery'. We have started a pilot training course, 'Solutions Focused Coaching', with a range of staff from across the South and South West Directorate.

The course is being run over three days and we have been practicing skills that enable staff and 'client' to think positively about current and past achievements, to validate and celebrate these achievements and to use these as the impetus for future change. So far we have completed two of the three days and it has been very encouraging to see how keenly staff have taken to these skills. They have often 'practiced' on personal and family issues but have also begun to use them within the service. We have tried to include staff from a very wide range of services and it has been very encouraging to note already how the skills can be seen to have a practical application in services as diverse as outreach and residential care.

It has been easy to see how these skills can help in one-to-one situations and I have been asked, "How can I relate this to group work?" To answer this I thought it might be helpful to tell you about two groups I was asked to speak to in the last few weeks.

1. Landlords and Landladies in Torbay

I was asked to speak about the Recovery Model to a group of people who provide private lodgings to people with severe mental health problems through the NSF Accommodation Plus scheme. The manager of the scheme was keen that my talk should challenge the 'caring' assumptions of participants.

Solutions thinking influenced the structure of my 'talk' in that I chose for my starting point not to start with recovery in relation to mental illness. Instead I asked the group to work in pairs about their own experience of recovery, "How have you managed recovery in your own life and what has worked for you?" The second part of the 'talk' allowed the members of the group to feed back the information from their partner. This was used to 'compliment' each individual person on their achievement in managing 'recovery' in their own life. This produced a long list of items which were 'owned' by the group. I then went through this list 'validating' each item in terms of 'recovery' from mental illness. At this point I was able to introduce the Recovery Model as a vehicle to take forward the groups own recovery agenda in terms of mental illness.

2. What is Schizophrenia? Members of Gemini Service

I was asked to talk to a group of Gemini members who had been given a diagnosis of schizophrenia, about 30 years ago, but no-one had taken the trouble to explain to them what they meant by schizophrenia. I decided to work from the experience of the members

started by looking at their experience of Health and Illness. We discussed the fact that you could be ill yet feel healthy and vice versa. This was something that the whole group could agree upon. This led on to a discussion about Mental Health and Mental Illness and the members were able to relate to the idea that even if you were 'mentally ill' you could experience 'mental health'. This understanding of 'mental health' enabled them to start to talk about how they managed their mental health. They were all on medication but most of them still experienced voices and delusional ideas. I was able to congratulate them on the way they had been able to use a variety of techniques, including medication, to successfully manage their voices and their 'mental illness' over the years. With this level of understanding it was then possible to explain to the group how people using the medical model understand schizophrenia while at the same time giving them permission to have other understandings of the symptoms they experience.

Giving the Goose a Hand - HOMEWORK

You will recognize within each of the preceding paragraphs a process of: engaging in shared experience; understanding or bringing to the surface ways to dealing with this experience; validating the achievements in managing these experiences; and then using this sense of achievement to look to new ways of managing in the future.

The challenge is for everyone within NSF who is in some way involved in service delivery to engage in this process. I would like everyone in pairs to do exactly what the landlords and landladies did. To ask the other person how they have managed 'recovery' in their life. To compliment the other person on their achievement and to observe how they receive the compliment.

The next stage is to take this information into a 'team' setting, where this is possible, and to share and validate these findings in the context of 'recovery' from mental health problems. The final stage of this part of the process is to use this 'understanding' to begin the process of thinking how this could influence, albeit in subtle ways, the service you deliver.

The next and most crucial stage is to engage with a person using your service to find out how they have managed their 'recovery' up to now and to congratulate them for these achievements. This will hopefully open up the possibility of exploring other ways of managing.

Please would you arrange for someone within your team to feedback to me the results of this Homework. I would like to have this information by 31st January 2001. If this is not possible still complete and send in the information. Thank-you.

Returns, comments questions to:

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Recovery So Far 5 The Goose's Christmas Quiz

Medication and Recovery

At the recent NSF Conference – ‘A Question of Choice – People’s Views of Treatment used in Mental Illness’ - Andrew Watkis, Assistant Company Secretary, Unigate, decided to experiment with his anti-psychotic medication by taking a dose during the Conference to see if it had any noticeable effect on him. He tried to observe any changes that he became aware of and invited the audience to comment on any changes they noticed. This was quite an interesting idea even if in practice the results were less dramatic. It did however clearly demonstrate that there were two different sets of people who have an interest in the outcomes of medical interventions.

1. The people who take the medication.
2. Other people who are affected by any changes in the person receiving the medication.

In the medical model there is a third group of people involved. These people often exercise enormous influence over the person taking the medication. These people are the medical and social professionals. These professionals have some interest in the views of the people above but their influence is often dominated by certain widely held theories about the role medication has in the ‘treatment’ of mental illness. We are all familiar with the theory: ‘People need to take medication for the rest of their lives because if they do not they are more likely to have further psychotic episodes and this could lead to an increased likelihood of the illness becoming chronic and having a poorer outcome.’

The history of psychiatry would suggest that many such theories have in the past been largely discredited over time. It is not that long ago that people were given repeated ECT as a treatment for schizophrenia. It is now rarely used in the treatment of this condition. Many ‘treatments’ have come and gone. A review of them would suggest that their proponents had sadomasochistic tendencies. The ‘treatments’ however were all well intentioned even if they did include: being strapped in a bath for 24 hours; injecting with rats brains; brain surgery, etc. Psychiatry seems to have the capacity to discard unsubstantiated treatments and move on to the next ‘treatment of choice’ without accepting any responsibility for the consequences of the redundant treatment.

How does ‘recovery’ seek to deal with these difficulties?

‘Recovery’ is neither for nor against the use of medication. The issue is much more about how people can be enabled to become more knowledgeable about medication so that they can play an active role in deciding how medication may or may not assist them with their recovery. We know that the theory that people need to take medication for the rest of their life is untrue. We know that about one third of the people who have an initial psychotic episode will recover completely, another roughly one third will have an episodic type condition where they can be quite well in between episodes and a further third will suffer from more continuous periods of distress. Of this last group some appear to get no help from the medication.

Clearly the first third do not need medication at all and it is in their interests to stop taking it as soon as the initial distress has abated. These people may themselves want to continue to take the medication to try to reduce the fear of having further episodes. They should be given all of the facts in an unbiased way so that they can make a judgement for themselves.

The second group, who cannot easily be distinguished from the first group until and if they have a further episode, may or may not choose to take medication for the same reasons as above. The difficulty is to know if taking the medication does prevent further episodes. If we assume it does the person taking the medication still needs to decide for themselves if they are better to take medication to try and prevent a further episode or to take steps to manage their distress at the time it is happening.

The third group of people, with a long term condition, still need to be involved in their own treatment. They need to balance the benefits of taking medication against the side effects. They need to consider if there are other ways of managing their distress. They need to be clear if there are any benefits to taking medication.

It comes back to the idea of professional staff becoming **‘people navigators’**. The role of the navigator is to give the pilot – the person taking the medication – all of the information so that they can make the choice that is most appropriate to them and their lives.

Interesting Footnote from Conference: The use of medication in the USA has become more of a partnership and agreement between the consultant and the ‘patient’ because of the fear of litigation. Perhaps we need to be more proactive in supporting people whose lives have been destroyed by poor medical advice. This has led to a much greater use of ‘atypical’ anti-psychotics and lower doses of ‘typical’ anti-psychotics.

The Goose's Quiz

Example 1: A young man is living in a supported housing scheme where he has a flat of his own. He is a young man who has fairly persistent ideas of persecution. He believes that the people who are involved in his care do very little to support him and that they plot to take him back into hospital where medication is forced into him. There is an increased likelihood of this happening if he comes off the medication they prescribe. He is on fortnightly injections of depixol. The side effects of the medication include impotency and he is unhappy with this as a treatment for a condition that he does not understand to be an illness. He has been through the cycle a number of times. He is forced to have the medication in hospital. He comes home feeling well mentally but does not like the side effects of the medication. He comes off the medication and becomes more paranoid about the people in authority. Anxieties arise because he becomes verbally abusive and eventually he is taken into hospital. The justification for keeping him on depixol is that the professionals know where they are and in particular when he stops taking medication. **Question:** What alternative approaches to the use of medication might be considered in order to get out of this cycle?

Example 2: A young woman who is in a residential care home who suffers from panic attacks as a result of intrusive thoughts. She is taking anti-psychotic medication. She said that the medication gives her no relief from the distress. She was not aware of any unpleasant side effects. **Question:** What approach would you take in relation to the use of medication?

Example 3: Young man who has had two psychotic episodes a couple of years apart. After first episode he came off the medication and felt fine over the last two years. His life revolves around cycling and keeping fit. He has been told he needs to continue to take medication indefinitely. He is very distressed as he cannot continue with his 'life' if he takes the medication. **Question:** How would you advise this young man about the use of medication?

Example 4: This older woman has been involved with mental health services over many years. She is very distressed by the side effects of a cocktail of medications. **Question:** How can you help?

Example 5: You have known Fred over many years. He has heard talks about 'recovery' and without discussing it with anyone he has come off medication about 3 weeks ago. He says he feels very well. **Question:** What do you do?

Answer 1. The reality is that the young man's behaviour is just as good a predictor as to whether he is taking his medication. The best chance of breaking the cycle might be to encourage him to take more responsibility for the implications of his behaviour. As a people navigator you could provide him with information on the use of oral medication to minimize the risk of being taken into hospital again. The chances are that there will be several failed attempts before learning takes place. Under the present regime the only learning that takes place is that he feels he is punished when the care team do not like what he has to say.

Answer 2. If you were to ask the young woman she would say that what she needs is help to manage the distress from the panic attacks. The medication may or may not be helping. It would be useful for the young woman to monitor the actual frequency and intensity of the panic attacks and the intrusive thoughts. It is not a problem for the young woman to take the medication, but it is not seen as providing a solution. Information about other medication and the implications of giving up medication could be considered in the light of the information gained from closely monitoring the distress.

Answer 3. Advice is not an option. Good information is. He needs to make choices about his life and how he wants to manage. He does not need to be told not to take his medication or to stop that is a decision for him when he is informed about all the facts and theories.

Answer 4. Involve the local pharmacist in looking into the efficacy of the drugs cocktail.

The role of the 'people navigator' is to help people manage their own distress. To help them to make choices recognising that they will sometimes make mistakes. Mistakes provide the opportunity to learn and to begin to take control. We need to recognise that medication is not the solution it is just one of the tools that may or may not be helpful to any individual.

Answer 5. Establish why he has told you this information and what he would like you to do with it. Try to get him to agree to tell or allow you to tell the mental health team. Discuss with him the possible consequences. Explain the implications of a recurrence of symptoms, the implications of withdrawal symptoms, and how he manages if he goes on improving. Consider with him what he would like you to do if you notice changes in his behaviour. He needs to be told at what point you would tell the mental health team without his consent.

Happy Christmas and New Year from Derek and the Goose

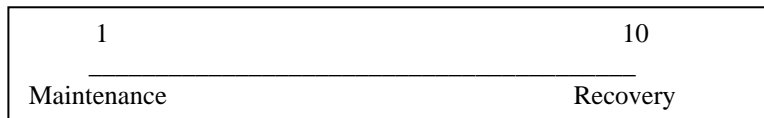
Recovery So Far 6 – The Goose Goes Ballistic

12 Steps Towards Recovery

The discussion phase within NSF in relation to ‘recovery’ is now drawing to an end. The next logical step would appear to be to ‘adopt’ the ‘model’ with all that that entails. Having begun to address this with members of staff in different situations and also reflecting on what has been learnt so far, this step does not appear to be quite so logical. There are two main reasons for this.

1. The model as we understand it is less of a ‘blue-print’ – An IKEA kit for service development. It is much more of a process with a set off key principles and values that need to be interpreted within the context of each service – principally by the people who use the services.
2. If the task is interpreted as one where the whole staff team needs to be ‘retrained’ it seems to present difficulties that may well prove to be beyond the resources of the organization and as a consequence the whole concept might fail.

We have recently concluded a training course in Solution Focused Coaching and one of the skills that emerged from the course was the use of ‘scaling questions’ to help people to focus on small step changes on their road to recovery. Services can be looked at as being in ‘recovery’ and somewhere on a scale between ‘Maintenance’ and ‘Recovery’ from 1 and 10.



Some of the principles and values associated with this shift are as follows:

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| 1. Monitoring Mental Illness | to | Expanding mental health |
| 2. Low Expectations | to | High Expectations |
| 3. Managed care | to | Self Management |
| 4. Social Isolation | to | Social Inclusion |
| 5. User Involvement | to | User Partnerships/Alliances |
| 6. Project staff | to | People Navigators |
| 7. Dependence | to | Interdependence |

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| 8. Service Led | to | Aims Led |
| 9. Safety/security | to | 'Feel the fear and do it anyway' |
| 10. Service for Life | to | Move-on |
| 11. Problem Focused | to | Solution Focused |
| 12. Building Based | to | Community based |

The road to 'recovery' can start by simply asking yourself where you are on this scale for each of these 12 factors. Wherever you are provides room for congratulations as you have already taken a brave. Then ask yourself what you can do within your service to move half a point or a whole point towards 'recovery'. Engage others in the process and you are well on the way towards 'recovery'. Celebrate every achievement!

Recovery So Far 7 – The Goose Needs A Friend

Social Inclusion

At a recent conference, I was asked to attend in Gloucester, the Severn Trust were presenting the results of an analysis of needs for their caseload across the city. They had undertaken this major piece of work to try to identify what people using services were saying about the services they receive and obtain some understanding of the unmet needs within the group.

My involvement in the exercise had been fairly minimal but I had suggested that they might want to use CUES as a self-assessment tool within their study and they had taken up this option along side the more rigorous Camberwell Assessment of Need tool. The results from the two exercises were fairly consistent with the greatest unmet need lying within the categories associated with ‘friends’, ‘family’ and ‘social life’.

This is not a particularly surprising result when the group was made up of people who had a diagnosis of schizophrenia or another psychotic illness and that they had been known to the services for a number of years. The result is however significant if we take this as the basis for trying to develop services that are designed to meet the needs of the people who use our services.

How do we design services that begin to address the need for people to make friends and socialise?

As luck would have it the conference took place in a building in Gloucester where Ron Coleman and the Action Consultancy and Training(ACT) team are based. Alison Cox, one of the team offered to meet me after the event to discuss ‘social inclusion’, a concept that I felt ill equipped to be talking about. As is often the case the interest in social inclusion bridged into the need to develop services to address the unmet needs described above.

We all have a need for family, friends and a social life. We gather around us people who make our life meaningful, rewarding, interesting, fun, intimate, etc. Alison introduced me to an interesting way of looking at these relationships. There are four separate categories of relationship, within this particular model, that are important to us. These can be shown in diagrammatic form as four concentric circles.

In the inner most circle ‘1’ we have our most intimate relationships – people we allow to get very close to us. (Husband, wife, partner, children, etc.)

In circle ‘2’ we have our close friends, people we confide in and feel close to.

In circle ‘3’ are the people who we would describe as friends, we send them Christmas cards, enjoy their company, engage in activities, work with, etc.

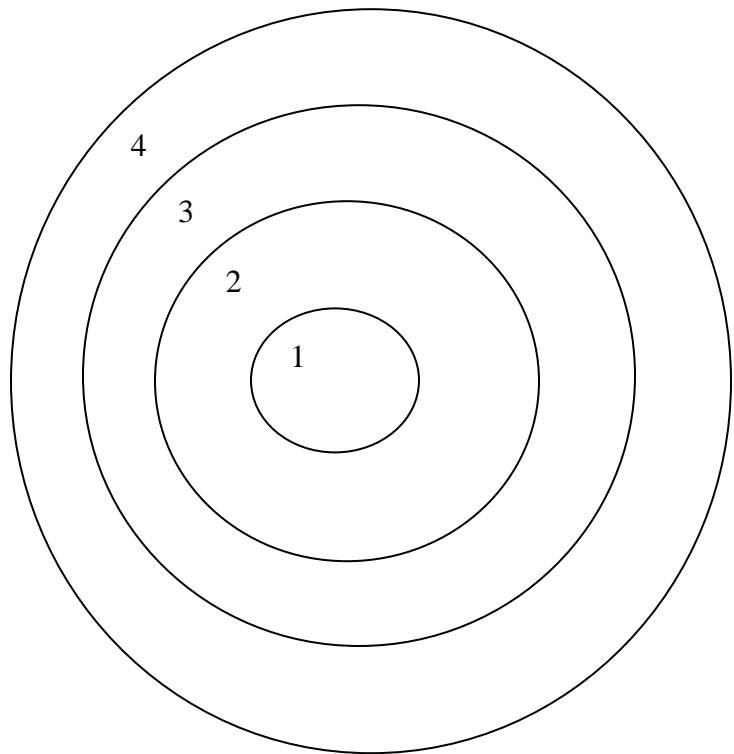
The outer circle are the people who we know who may have some dealings with us because of their position. Doctors, schoolteachers, people met through work, etc.

If we consider these different relationships in the context of the people who use mental health services and the study done in Gloucester we can begin to understand how we might begin to build an approach to working with these people to try and help them to have happier and healthier life styles.

For a healthy life style it is important to have people in each of the bands.

Band '1' is a small group of very select people who are unique to you.

Within band '2' we have a larger group of people who we select and who also reciprocate in selecting us.



The band 3 people are much less 'defined'. There is little or no selection involved and people will come and go without attention being drawn to their status. They are however very important in the sense of your feelings of belonging to a 'community'.

Band 4 people are defined by their position. Their relationship to you is dependent upon how important their position is to you at any point in time.

With regard to mental health services the first thing to say is that for many of the people who use our services they may have very few people in any of the categories except band '4'. They therefore look to the people who have an 'official' function for closer friendships. This rarely works as very few people will move from this band to any of the inner bands. We can I am sure all call into mind people who have sought our friendship in band '2' and exceptionally band '1' when the appropriate relationship is band '4'.

In many ways the most important band is band '3'. In many of our services we only provide the opportunity for people to meet and engage with a very narrow group of people – the people who use mental health services. Social inclusion starts with the supposition that people who use mental health services have a right to meet and engage with a broad spectrum of people according to their individual interests. Services need to shift their emphasis away from the traditional ghetto style of service delivery to creating opportunities both outside and inside services for social interaction on a much broader scale. Do we in fact need to be developing services that separate people from the rest of the community. Would it not be sounder to develop opportunities for communities to come together to share interests. We have seen a proliferation of floating support services within housing the time has come to see a similar development of floating support enabling people to use community centres, education centres, and to support employment.

If we can enable band '3' to develop both in terms of numbers and cross-section of the community then bands '1' and '2' will look after themselves. Any attempt to develop services to directly expand these bands will be doomed to failure as they are highly selective and need to remain so.

This approach to social inclusion also directly questions the need for a 'relationship policy' within an organisation such as NSF. If a member of staff were to move from band '4' to any of the other bands this can only be by a process of mutual selection between the people involved. If we believe in social inclusion then we cannot 'outlaw' this possibility. It will be said that this can leave vulnerable people open to exploitation and abuses of power and trust. This is of course true and it is to these things that policy must be directed not against genuine relationships. A relationship may in some instants create difficulties within a service, this also needs to be recognised and managed, not outlawed. When people who find it hard enough to become engaged in any sort of relationship find a meaningful relationship it is a time for celebration not disciplinary action.

26/07/04

Recovery So Far 8 – The Goose’s Errors and Misdemeanours

Recovery So Far 7 seems to have raised a storm. It is always good to provoke a debate but I think I need to comment on the last paragraph as the issues raised are difficult and could potentially divert attention away from the importance of Social Inclusion. Social Inclusion is the movement away from services that are designed to create mental health ghettos. For example we have seen an increasing involvement of adult education within some of our services. Adult education are often more than willing to provide a tutor for upwards of eight people. Wherever possible we should be looking to be part of mainstream groups or inviting people into our services from the community who might want to take part in the class. Social Inclusion is about enabling people to build up their circles of support from as many strands of society that they see as important them and their sense of themselves. Social inclusion is about not losing in the first place those support systems that have worked in the past. These often start with the family and spread from there. We need to be working with people to strengthen the way these relationships can work for people to help them take control of their own mental health. CESP provides one avenue for this we need to develop others.

In Recovery So Far 7 I looked at how staff might get involved in these networks of support and the implications that this might have for a ‘Relationship Policy’. I will try in the next few paragraphs to deal with the concerns that have rightly been raised.

The first point I would make is that the role of mental health intervention as stated to me by someone who has used mental health services should be rather like the ‘plumber’ who you call in to mend your pipes. When the pipes are mended to your satisfaction the plumber then goes away and leaves you to get on with your life. You may call him in again when necessary but he remains very firmly in ‘circle 4’. All too often in the past an invitation to help with someone’s mental distress has been a ‘sentence for life’ and it is not surprising that many people who use services have seen the people in ‘circle 4’ as their close and sometimes only friends. I remember vividly the pain experienced by people who had been attending a Social Services run day service in Bristol when they were told that the service was to be closed and NSF were going to run new services. We were told very forcefully by both the staff and the people using the service that we were breaking up their ‘family’.

In the normal course of events we would like our staff to stay in ‘circle 4’ and to be ‘a plumber’. However there are some difficulties with this that we do have to consider within the policies and procedures that we rightly need to have in place to protect staff and people who may be vulnerable. Staff for a variety of reasons can find themselves alongside people in ‘circle 3’, this may or not be a problem, but once in circle 3 there is the possibility that movement occurs towards ‘circle 2’. We may all agree that a further move into ‘circle 1’ is likely to interfere with a staff member’s ability to do their job but we might well find it difficult to agree at what stage between leaving circle 4 and arriving at circle 1 there is a need to intervene. This is one of the reasons why it is difficult to have a pure ‘Relationship Policy’ as opposed to policies and procedures for dealing with the implications of relationships between a member of staff and a person who uses

services. The same issues arise, very often, when there is a relationship between two members of staff. There are some particular scenarios that need to be considered.

1. For many years, and probably increasing in the future, we will be appointing people who have themselves had mental health difficulties. These people, particularly in rural areas, may have existing relationships with people using our services. These staff will need help and support to manage the implications of these relationships in ways that are appropriate to the development of the service. If the implications of a relationship between two people becomes detrimental to a service then this will have to be dealt with. Policies and procedures will need to be in place to deal with these implications. The management of this will not differ greatly from current practice. The difference is that it is the implications of the relationship that are the concern not the relationship itself.
2. Increasing we will be asking staff to work with people in contexts where they share a common interest (as this is one of the most effective ways of cultivating . As a member of staff you may be a beekeeper and you may arouse this interest in individuals who come to the service. This may lead to you and others becoming members of the local Beekeeping Association. This inevitably leads to a shift from circle 4 to circle 3. As above staff need to be helped with this, but here again if the implications of this relationship affect the ability to deliver the service this will again have to be dealt with.

People have raised with me the concern over the imbalance of 'power' within relationships where the person who uses services may have been traumatised in the past. Nothing that I have been saying either in this newsletter or in the previous one excuses exploitation of vulnerable people. Exploitation of any kind undermines the ability of staff to deliver the service and this needs to be dealt with decisively.

User Leadership

I would like to correct the reference to 'User Leadership' mentioned in Recovery So Far 6 as being one of the goals within a 'recovery' orientated service. As has been pointed out to me if this becomes a goal then we are in the business of reinforcing the 'mental health ghetto'. More appropriately the goal should be 'User Alliances and Partnerships' where the aim is to involve people within the running of services in ways that built self confidence and self esteem.

Independence

Also in Recovery So Far 6 I have referred to 'Independence' as the goal opposite 'Dependence'. In line with the issues raised above in connection with Social Inclusion the goal should be 'Interdependence'.

I hope the goose is now on track again!

Recovery So Far 9 – The Goose Speaks Out

Underpinning Value System

1. People

- ‘People’ experience mental distress.
- People are experts in their own mental health - Everyone has ‘Insight’.
- Recovery is a process whereby the individual takes back control over their own mental health.
- Taking back control involves the development of self management strategies including:
 - (i) Self-management of medication.
 - (ii) Self management of voices.
 - (iii) Self-management of early warning signs.
 - (iv) Advance directives for the management of crises.
 - (v) Self-management of risk.
- Recovery is a process of growth involving the transformation of ‘disability’ into ‘giftedness’.
- Recovery involves re-building networks of support including family and friends.
- Recovery is a process of change and fear of change is part of that process.
- Everyone who begins to take back control over their lives by however small a step is on a pathway to ‘recovery’.
- People who experience mental distress have the same rights and responsibilities as other members of society.

2. Services

- The primary function of services is to help people ‘recover’.
- Services provide opportunities for people to take control over their environment.
- Services provide an environment that facilitates self confidence, self esteem, self awareness and self acceptance.
- Services provide opportunities for people to access objective information about the management of their mental distress so that they can make informed choices.
- Services facilitate social inclusion.
- Services provide opportunities for people to engage in self management.
- Services provide a holistic approach to the needs of people.
- Recovery is assisted by ‘people navigators’ who have skill, expertise and experience, but who allow people to make their own decisions, even if this leads them into ‘turbulent waters’.

Recovery So Far 10 - Resurrection of the Goose - People Navigators

With Job Evaluation reaching a climax I thought it might be interesting to share some thoughts about the role of People Navigators. Based on the 'recovery journey' that any person might take the role of the People Navigator might be to help the person by guiding them, giving them information, sharing experience and being there to support them with their fears and uncertainties. These are some of the areas that could be important:

People Navigators try to help people feel positive about themselves and their experience.

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 own recovery.

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

People Navigators support people to self-manage medication as a tool that may help them recover and to challenge the impact of unwanted side effects.

People Navigators enable people to access resources that will help them manage their voices.

People Navigators assist people to respond to early warning signs and triggers that may affect their mental health.

People Navigators assist people to plan for a crisis.

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

People Navigators help people to recognise their own 'giftedness' and encourage them to grow in self-knowledge and awareness as unique and valued human beings.

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

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

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

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

A Final Message From The Goose – Recovery So Far 11

Recovery – Where to Now?

Last week I had the good fortune to attend a Recovery Conference at UCE, Birmingham. The Conference, which was attended by over 200 people, and with over a hundred people turned away, heralded the inauguration of the West Midlands Recovery Network. The Network has already received support from the West Midlands Partnership that has been so influential in recent years with regard to mental health policy development nationally. The momentum for change is gaining ground, and a message of ‘hope’, for people with experience of mental distress in their lives, is now firmly on the agenda.

The main speaker and workshop leader was Helen Glover¹, who had travelled from Australia, to inspire and enthuse the delegates with her courage, her humanity, her vulnerability, and her message of hope and ‘giftedness’. Helen has struggled for many years of her life with mental distress. She is still struggling. She has experienced acute depression, psychosis and has been deeply suicidal on many occasions. Helen has experienced real torment and has caused herself physical harm to the extent that she now has to be fed through a drip and has a colostomy bag. Helen was joy to listen to! To learn how she has been at the forefront of developing recovery principles within the mental health system in Australia. Helen does not see recovery as a process or system, it is a deeply human experience that sees and understands people as being so much bigger than their distress. She has been able to regard her disabilities as part of her humanity, her gift. They are often the inspiration to be able to help, support and ‘hold the hope’ for other people who experience distress.

What remains with me most from Helen’s talk is the idea that it is not what we do when we are supporting people with their recovery, it is how and when we do it. A Consultant Psychiatrist who attended the Conference asked me what was the difference between ‘rehabilitation’ and ‘recovery’. Rehabilitation is a system within which people are processed. They pass through as they complete tasks and boxes are ticked. Recovery is about being connected to individual people, sharing their humanity, and being able to provide support, or give a kick up the backside, out of love.

Yes, there are things we can do to support recovery. We can help people to become more self aware, we can validate their ‘life experiences’. We can create environments that build self-confidence and self-esteem, and we can support people to accept themselves, warts and all. We can ensure that everyone has access to information that helps them to make real choices about their lives, we can enable people to develop skills that help them to get through when times are bad. We can support people with the relationships that are

¹ Helen Glover is a Social Worker with an education background. She embraces her lived experiences of recovery from mental illness in her professional work. She has written a paper, “Challenging Mental Impotence, A Perspective from Queensland, Australia”, which can be obtained through the UCE, Centre for Mental Health Studies, the paper is edited by Piers Allott, Mental Health Recovery Educator, UCE, 2001.

important to them but if we do not give of ourselves and our own humanity we will fall short in every area.

Much has been said about the fact that 'recovery' has grown out of the 'user movement' and there are many people who believe that it is only 'safe' within that movement. Kevin Childs, from the USA, who also spoke at the Conference, is dedicated to 'user run' services. He does not believe that 'the system' can change. We must ask ourselves, "Is recovery safe in our hands?" What do we intend to do with recovery? Is it a business imperative? Is it a way of being one-step ahead of our competitors?

- Recovery is a belief. It is a belief in the humanity of every person. It is a belief that every person has the potential to 'recover'.
- Recovery is a commitment to every individual and to the 'gifts' they bring.
- Recovery is not something you do to people, it involves sharing the ups and downs of life's journey.

People who acknowledge their own vulnerability and distress do have something special to offer people who use services. We will need to consider how to support people who currently work in our services, and who we recruit in the future, to be able to share their life experiences.

A theme that arose more than once during the Conference was the need for 'magic' in peoples' lives. A talk was given by Maria Ford about 'Swimming With Dolphins'. It has been discovered that these mammals have a profound affect on the lives of people who come in contact with them. Some Dolphins, who normally live in community groups, break-off from the herd, and become 'ambassador' dolphins and it is these dolphins who seem to have this magical effect. A trip is planned for a group of people to go to Dingle Bay, in Ireland, where the magic of 'Fungi', the dolphin, has been documented and researched.

Kevin who I mentioned above spoke mainly about Websites that have information about recovery. Also attached is a list of the Websites that he has recommended.

The only service that has been set up in the UK on 'recovery principles' is Anam Cara in Birmingham. Rob Kerrigan talked about his personal journey and how this has influenced the way he works at Anam Cara. The project is run by a Voluntary Organisation, CHANGE, is a Crisis House providing an alternative to hospital admission. The house is run by people who have had a life experience of mental distress. The project, which is being evaluated by the Sainsbury Trust, has been highly successful and a second house for Women only is opening at present.

NSF were represented, at the Conference, by Eve Thompson and Margaret who talked about the importance of Family and Friends in the recovery journey. Eve and Margaret have both trained in Behaviour Family Therapy, as part of an initiative sponsored across

the West Midlands, and this has been not only valuable in helping other families to deal more effectively within communication problems, but they have both found it invaluable in solving issues within their own situation.

Piers Allott, Mental Health Recovery Educator, at UCE, was the host and driving force behind the Conference. He has a personal commitment over many years to the development of recovery orientated personal supports and services in the UK and beyond. By the end of the Conference there was a commitment by most of the delegates to build on the work done in the two days and to create the Recovery Network in the West Midlands.

NSF will need friends and allies to go down the recovery path. It will be important to join with others on this journey and to be an active supporter of initiatives like the Recovery Network.

Websites to investigate:

<http://groups.yahoo.com/group/WestMidlandsMentalHealthRecoveryNetwork>

LEEP – developing Lived Experience Evidenced Practice & Establishing The Concept of Recovery in Mental Health in UK.

<HTTP://mentalhealthrecovery.org.uk/7.htm>

Mary Ellen Copeland – Mental Health Recovery Self Help Strategies

<http://www.mentalhealthrecovery.com/>

Jean Campbell – The Consumer Studies and Training Program

<http://www.cstprogram.org/>

Zangmo Blue Thundercloud

<http://home.earthlink.net/~sallyclay/>

Bazelon Law Centre for Mental Health – see Advance Directives –

<http://www.bazelon.org/advdir.html>

Search Engines

<http://cui.unige.ch/meta-index.html>

People Who Net

<http://www.peoplewho.org>

Internet Tutorials

http://k_c.home.att.net/tuts.htm

A Home in Cyberspace

http://www.cyber24.com/html1/1_13.htm

National Summit of Consumers and Survivors
<http://thesaint.home.att.net/summit2000.htm>

Disability Directory
<http://thesaint.home.att.net/dd.htm>

Alcoholics Anonymous
<http://www.aa.org>

Narcotics Anonymous
<http://www.na.org>

Recovery email lists
<http://McFlurryLove.home.att.net/recovery.htm>

The Report following my work on Recovery over the last eight months is more or less ready to go out. Hopefully it will be with you very shortly. My concern is that it may read as though recovery can be done by following a set of guidelines. As is indicated at the beginning of this paper recovery is much more about the person, whether that person is a member of staff or someone who uses services, a family member or a friend.

As I will no longer be on the payroll for NSF I will sign off by giving my new details. My new Website is in the process of being constructed. It is beginning to take shape and its progress can be followed on:

<http://www.maesyfed.co.uk>

On the site you will find details about the creative holiday breaks that we have planned, opportunities for Respite, details of the Green Gauge Consultancy, and the craft agency that we are developing.

My other contact details are:

Address: Maesyfed
Penybont
Llandrindod Wells
Powys
LD1 5UA
Phone/fax: 01597 851951
Email: derekt3@hotmail.com

I hope to remain involved with the development of the Pilot Sites and I am available for Conferences and Training for Recovery. Recent 'recovery events' have included; a presentation to the Public Affairs Committee, a workshop for the Operations Team in Dorset, and with people using the Gemini service in Oxford.

Derek Turner

28th May 2001

Recovery So Far 12– Goose Sighted in Newtown

Rekindle – A Service to Live For – Not a Service For Life

I was merrily helping with a ‘Show Garden’ at the NEC, BBC Gardener’s World Live Exhibition, (that’s another story) when a friend’s mobile phone went off. His wife was on the phone asking for me. It turns out that a new service in Newtown was in difficulty as the member of staff had left and the Grand Opening of the service was next week. Could I help. After a few phone calls I discovered that it was a new NSF Cymru service and they would be very pleased to have some help while they recruited a new member of staff.

Always delighted with an emergency I agreed to help. Having had a chat with Janet Randles, NSF Area Manager for North Wales it was agreed that I should put in what time I could over the next few months to get the service off the ground.

Well here I am in Mid Wales and all this ‘recovery’ research under my belt it is an opportunity not to be missed. Having checked with Janet that ‘recovery’ was not an ‘alien concept’ I was on my way.

The first thing I was struck with was the fact that there is only one member of staff - a real opportunity to make alliances with the members to share the responsibility for the service.

The next thing I became aware of was that there was already a Day Service in Newtown which has a good record for providing a wide range of traditional Day Care activities. Another opportunity – there would be no point in providing a duplicate service.

The service came about because a group of people in the area felt that there had to be a more positive future for young people living with mental distress. They formed themselves into a local fund-raising charity and then asked NSF to run the service. Another opportunity – no ties to statutory funding and the maintenance approach.

At the end of the first week I have made contact with two volunteers both of whom have had experiences of mental distress that has made it very difficult for them to get back into paid employment. We have had a discussion about what a service might do to assist them to deal with the difficulties they experience and how they can help the service develop in a way that solves these difficulties. They have agreed to help me to run the service and I have agreed to support them within the service to deal with things that help them to gain the confidence to be able to move on from the service into employment.

Some of the things that we have discussed so far include developing an information resource around the things that would most benefit these two people. One person is going to look into Hearing Voices Groups, Medication and Side Effects and the other is going to explore Self Harm.

We are going to share the tasks of running the office as both of the members/volunteers feel they need to improve and develop confidence in this area. They are going to sit in on networking meetings and be involved in explaining to other agencies what we are trying to do.

We are setting time aside to look at tools and resources that help them to understand and take control of their mental health and to see if drawing up recovery plans will help one of the members/volunteers to plan for his next CPA Meeting – but that is for next week.

We are under way and already we have possible referrals. We have already discussed how this might affect the way the service is to develop. There is a lot more to do and we have a commitment to do it together.

As usual I am very excited by the prospects and feel very privileged to have met two people who are prepared to work with me. I will continue to write and tell you how it is going in the hope that it will add to the work that we have already done together on 'recovery'.

Derek Turner

26/07/04

Recovery So Far 13– Goose with Ambitions to Become a Swan

Progress at Rekindle

My time at Rekindle as Acting Co-ordinator is rapidly coming to an end. It has sped by all too quickly and I have begun to reflect on what has been achieved and what I have learnt over the period. Trying to remain true to the ‘recovery principles’ that I have been exploring over the last couple of years has proved to be difficult, very challenging personally, but also very rewarding. There have been the usual problems associated with setting up a new service, particularly one that has not been funded by the statutory purchasers. It is not always easy to explain what the service will be doing when you are still working out in your own head how it will function and this leads on to the inevitable snow build up of referrals.