STOPOVERS ON MY WAY HOME FROM MARS

A journey into the psychiatric survivor movement in the USA, Britain and the Netherlands

MARY O'HAGAN

My madness took me places I had never been.

One dark night the long polished corridor turned into a glowing ramp and the ladies' dormitory at the end of it became my private spaceship bound for Mars.

Mars was incomprehensible. No-one else had seen it through my telescope. There were no maps or signposts there. No-one else was with me to point the way. So I turned back.

I know something on Mars is hiding from me so I've been collecting clues on how to find it during my stopovers on my way home from Mars...

ACKNOWLEDGEMENTS

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EXPLANATION OF TERMS

The following groups of terms are used interchangeably throughout this report.

Madness (any condition judged to be psychiatric)

- crazy
- mental illness

Current or former psychiatric patient

- survivor
- consumer
- user
- client

Conventional services

- psychiatric services/system
- mental health services/system
- psychiatry

Mental health workers

- mental health professionals
- professionals
- workers
- providers

Survivor participation

- user/consumer participation
- power sharing
- partnership

Self-help

- support

Self-help alternatives

- self-help projects/initiatives
- alternatives

EXPLANATION OF TYPE STYLES

Normal text

The author's words –

- normal text indicates the main text
- Bradley Hand ITC indicates my journal

Italics

- *Quotes from other survivors*

MY JOURNEY BEGINS

My psychiatric experience

I was eighteen and a terrifying expanse of uncharted life lay in front of me. Alone in my university hostel room, grieving for my grandmother, I began an eight year rollercoaster ride through elation and despair. I lay breaking under my blankets like a young stem that has carried too much; all the meaning in my life drained out of me and I lost my self in a formless void. Concerned far away faces peered at me down a long black tunnel and took me away to be diagnosed, hospitalised and stripped of my clothes, credibility and dreams.

One day my hospital bed became my raft to nowhere, and I clung to it terrified of losing myself forever into the cold, unyielding sea. Then, a myth appeared from the ruins of my despair and I recited it like a long lost prayer.

"An old woman and her grand-daughter lived by a great ocean. Every day the old women went fishing. She yelled in awe to the ocean, 'Let me take the life out of you with my net.' She always returned with fish and cooked them for herself and her grand-daughter. One day she gave some of the fish to her grand-daughter and said 'Cook these for yourself'. The girl wailed 'I can't'. The old woman replied 'You must find your own power'. But the girl didn't understand and went to bed hungry. That night the girl woke from her dreams to a booming voice from the sky: 'You have the power of the old woman and the great ocean flowing into the core of you. Now, take meaning from the rawness of life and cook it for yourself without fear'."

The ocean and the old woman and the booming voice spoke to the core of me while my mental health guardians skated across the surface of my pain making small scratches with their inadequate science. They told me gravely that I would have mood swings for the rest of my life, and that drugs were the only things that could help me. I passively accepted their verdict for a marginal life and it took me years to question their self-appointed monopoly on competence and insight.

They left the myths in my well, waiting to be unravelled. I suspect that many of them remain there, untapped, in tight expectant bundles.

My role in the survivor movement

My mood swings died away. I was angry and amazed at how the mental health system could be so ineffective. There had to be a better way. I searched in the library not quite knowing what I was looking for. And there it was, a book called "On Our Own" by Judi Chamberlin. It was all about ex-patients who set up their own alternatives to the mental health system and it set me on my journey into the psychiatric survivor movement.

In 1987 I set up the Auckland group, Psychiatric Survivors, the first self-help group of its kind in Aotearoa/New Zealand. The organisation runs support groups, drop-ins and accommodation. We produce and distribute information for survivors and have a role in local mental health politics. In this report I've often compared Psychiatric Survivors to the groups I visited.

I wanted to find out what survivors were doing in other parts of the world. At the end of 1989 I heard that I had been granted a Winston Churchill Fellowship to go to the United States, Britain and the Netherlands which I did in March, April and May 1990. My visits were mainly to survivor run self-help organisations as well as to a few services and health promotion organisations that were trying to get survivors to participate in decision making.

My travels helped me enormously to sharpen my own vision for the survivor movement. I can more easily identify the things that inhibit and enhance our clarity of vision and the energy to pursue that vision. In doing this I have discovered that our movement faces not only opportunities but dangers as well, in our various attempts to create an alternative world which values our experience.

This report

This report is not a tidy descriptive chronicle of my trip. It is one person's reflective journey through a mosaic of experiences which I have stuck together with pieces of text, my journal extracts and quotes from other survivors. It is not an objective assessment (if such a thing exists) and it unashamedly contains unanswered questions, contradictions and risky generalisations.

Most of my visits to survivor organisations were brief and at times I have questioned my capacity to understand them well enough to make fair comments. On the other hand outsiders looking in, no matter how briefly, can

sometimes see with more clarity than the people who are immersed in their particular organisation.

I had reservations about some of the survivor organisations I visited which has made the writing of this report difficult. I have to be honest about my responses but at the same time I don't want to dump on my peers who were usually helpful and hospitable. For this reason I have changed the names of the people who talk in this report. And in the main text I have deleted the names of the organisations I visited. They are listed elsewhere. Unfortunately ours is a small movement and the people and organisations may still be recognisable to some.

This report is very negative about the mental health system. I make no apologies for this. However, my righteousness is always tempered by the sobering knowledge that if I had been a mental health worker instead of a survivor I would probably be all the things I criticise them for.

I start with survivors experiences of the mental health system then their visions for an alternative "culture of madness". A discussion on the survivor movement follows. The rest of the report looks at self-help issues - what it is, what it isn't and organisational issues.

STOPOVER 1
SURVIVORS IN THE SYSTEM

How do survivors experience the mental health system?
What are their main issues with the system?
Can the system ever value our experience?

Jenny (USA)

Basically what psychiatry does is a failure; very few people get better and the mental health system creates a lot of chronicity. The World Health Organisation has done a cultural study of schizophrenia and found that you have a better chance of not becoming a chronic patient in a third world country than you do in the west.

DEVALUED EXPERIENCES

My first stopover was not a place, but that devalued 'area' of experience people call madness. I wanted to know about other survivors who felt devalued by the mental health system. And I wanted to see how the survivor movement transformed that devalued experience into something good.

The survivor movement exists because we are not happy with the way others have responded to our madness. Although some people who have used psychiatric services are happy with what they got the accounts that follow represent the experience of many survivors both in the movement and outside it.

Many of us believe that as survivors we have been negated and oppressed; often in subtle ways, sometimes blatantly. We get the message from the system and society that our psychiatric experience has no value; to others it is meaningless, idiosyncratic, uncontrolled and frightening. Many survivors have discovered that we cannot live creatively or comfortably with such devalued experiences. Our movement gives us a framework to put value back into our experiences. While we do this we need to understand how the mental health system has impacted on our lives.

I talked to many survivors about their experiences of mental health services, treatments and rights. These experiences were remarkably similar in all the

countries I visited. Virtually all the survivors I talked to had been hospital patients and this was generally where they felt most powerless and devalued. However, they do not see community based services as the great liberator. Usually 'community care' just rearranges the old fortresses of paternalism and neglect into mini-institutions, inadequate community services and restricted opportunities for survivors.

SEVEN SURVIVORS' STORIES

Ingrid (Netherlands)

Ingrid is a young Dutch woman who was subjected to 19th Century style psychiatric abuse in recent years. She is a quietly spoken, fragile woman caught in the horror of her own self-abuse by burning and cutting. The services responded to this by force and Ingrid's self-abuse continues.

I can say something about my experience but it is very painful. I was in a severe ward, with forced feeding, tied up in a chair by my wrists and my feet in leather. In the night they put me on a bed naked and tied my hands and feet. They give me shots of medication but I didn't want it. I called a lawyer but the lawyer called my doctor, and then said she couldn't help me. It was hard to deal with.

It is humiliating in the cell. I had no sheets and only one blanket and a pillow. The door was locked. I had to put out my clothes. Last time they checked my pockets and felt my body. Everything was plastic so I couldn't throw anything on the floor or against the wall. The teaspoons were breakable and I cut myself with them. It was the only thing I could think of to do.

Brendan (USA)

Brendan, from the United States is a survivor and clinical psychologist now working for a survivor organisation. He wasn't abused in the way Ingrid was but he did sense a more subtle abuse taking place; one which inhibited people's recovery by sapping their hope and initiative. Brendan was told he may not be able to work for the rest of his life. Without his own initiative in defiance of these gloomy predictions Brendan doubts if he would have recovered.

I voluntarily sought help in a private hospital. It was a horrifying experience... I saw other patients who were not encouraged by the staff to develop termination; they were kept in a passive role and were not expected to get any better. I think that is the most damaging thing that professional systems do to

us; I think it's worse than if they beat us up or drug us into oblivion, or shock us with ECT. Those are all horrible things but I think the worst thing they do is to actively encourage loss of initiative.

Suzy (USA)

Suzy who runs a drop-in in California was illegally detained, tied up, beaten and sexually abused at an expensive private psychiatric facility.

I was an upper middle class spoilt person, very materialistic but not happy. One day I woke up and didn't know who I was. It was like the first free day of my life. It was a breakout not a breakdown, like having a clean slate again. But my family didn't see it that way and they sent me to a psychiatric institution.

Suzy was locked in a security room for two months in her underwear, and told she would not be let out until she said her name, which she didn't identify as hers at the time.

They treated me like dirt and I even started looking that way because I couldn't take care of my appearance. You become their stereotype which initially is all in their minds. They make you into that stereotype, and down the line you start believing it. When you believe it, it is almost all over. You become what the stereotype is. In the end I said what they wanted me to say. I learned to say what they consider appropriate and acceptable.

Virginia (England)

Virginia lives in the south of England where she now works as a freelance research psychologist. Like Suzy she is aware that becoming a mental patient involves taking on imposed roles. She spoke of this incident with quiet humour while she stroked her contented cat.

The psychiatrist said I could use the hospital as an asylum, and I immediately thought of lunatics. I took that role on; right I'm a lunatic so I must be mad. I broke some crockery on the ward because I thought if I am mad I can do that. That behaviour seemed to fulfil their expectations. It was an angry response; if they call me mad I will be mad. I joked about it. I met a friend who I still have in that hospital and we played at being mad by eating flowers and things like that. I have to say that for someone as miserable as I, it was a relief but it didn't help me to live my life outside.

Brett (England)

Brett from Nottingham, England experienced intense frustration getting the attention he needed in hospital. When he responded to this with a prank which would be tolerated in other situations, the staff didn't take his protest seriously. Brett was energetic and eager to entertain us with his experiences but I could tell he had been stung by them.

In the hospital they stressed that they have an open-door policy. This guy told me if ever I want to talk things out I could come to the office and know that the door would be open for me. The first time I knocked on their door, the staff waved me off saying they were busy changing shifts. The next time was their tea break. The next time they gave some other excuse. Then they said it was putting to bed time.

That night I took the door off, and then took it up to the main reception. The first thing in the morning ...I said I had removed the door to ensure the ward had a genuine open door policy. I have been through University where that sort of joke or protest was acceptable. Of course in the hospital it wasn't. The staff told me I did it because I was mad. I found that very demeaning.

Fiona (England)

Fiona from England is a Social Worker and a lesbian as well as a survivor. She had interesting experiences combining these sometimes contradictory roles.

Because I was a mental health worker they couldn't talk down to me quite so much. But the biggest thing was it made them treat me differently in one of two ways - either they treated me as a fellow professional who wasn't really having problems, or else they told me that I was not suitable to be a Social Worker. They had to either negate my feelings or my professionalism. They couldn't actually see me as being both a professional and a user; otherwise they would have to accept the fact it could happen to them.

Fiona also experienced the system's response to her lesbianism, which is another way of being that is devalued in our society.

When I first told somebody in hospital that I was a lesbian their reaction was 'It's just a stage you are going through'. On many occasions they would not touch me, because I was a lesbian. I had just ended a relationship with another woman and we had a child. I went into hospital because I felt so bad. They couldn't appreciate that I had lost my child and my partner and that seems

pretty prevalent. I know one person who told her psychiatrist that she was a lesbian and he told her she needed a good fuck.

Steve (England)

And of course being black in a white mental health system is probably the most alienating experience of all.

When Black people become psychiatric patients in Britain, they get second class treatment. If you go to your GP you are likely to be pushed onto some of the most junior doctors. Most Black people enter the psychiatric system via the police; usually sectioned and heavily medicated. There is no kind of talking therapy offered to us. We are put on the fringe of the ward; we are not involved in anything. We feel isolated; nobody wants to talk to us. There is none of the food you normally eat at the hospital so you have to eat what is there.

It doesn't make you feel good about yourself if there is nothing around you that speaks of your reality.

You see they are all white, and our experience of the white society has been oppressive and negative. For example, you have just been shoved aside by your GP, and been dragged in by the police. These are all symbols of authority. When you arrive at the hospital, a white professional walks in wearing a pinstripe suit. He doesn't take you seriously; he just writes out the medication and asks very superficial questions. You think 'Oh no, not again, I had better not say what I think or feel'.

A DEVALUING MENTAL HEALTH SYSTEM

All these survivors, in some way, felt devalued by the psychiatric system. The features of the system which survivors feel most devalued by are the medical model, the use of psychiatric drugs and ECT and forced treatment. These are also among the most important concerns of the survivor movement.

THE MEDICAL MODEL

The medical model claims that mental problems are physical illnesses which need to be treated by physical means such as drugs. This is the most dominant model in the mental health system. The medical model places a lot

of power at the hands of experts and because it is so deterministic, can put survivors in a very passive, disempowered role.

Suzy (USA)

I get scared at people who believe in the medical model; because it leads to programs that are totally hopeless. If you think that you are going to be sick for the rest of your life, and that is what the system is based on, there is no getting out of the mental health system because the assumption is you are going to need support and monitoring for the rest of your life. It's a very pessimistic model. I am against the medical model not so much because it is true or false, but because it is so pessimistic and not very practical. It doesn't help people.

PSYCHIATRIC DRUGS AND ECT

Drugs are by far the most common psychiatric treatment. Psychotherapy is usually more available to people with money and less debilitating problems; however many survivors in the movement believe psychotherapy can be as oppressive as physical treatments. Most of the survivors I talked to didn't support the use of drugs in psychiatry and were even more opposed to ECT (shock treatment). Some people were concerned that there had been an upswing of biological psychiatry in the last 20 years. Drugs are cheap, fast acting and usually sedating which makes them the number one option in the mental health system. Survivors sometimes complain that drugs are an internal straitjacket, that they obscure an important learning experience and that some of them have debilitating side-effects.

Suzy (USA)

Our minds have a way of helping us grow. Things that look crazy to other people can be growth experiences if they are not interfered with, which they are of course with drugs. We don't know how to get to the other side because we are never allowed to go there.

Kate (USA)

In New York I heard Kate Millet, a survivor and feminist author, debate the medical model with members of the American Psychiatric Association. She slammed the use of neuroleptic drugs.

There is a final abuse of medicine here - the widespread enforced consumption of toxic drugs. We are witness to an utterly unprincipled betrayal of the Hypocratic Oath which enjoins all practitioners upon the human body to do it no harm. Harm is done, and done consciously in full knowledge that it is harm. The American Psychiatric Association itself, has acknowledged that the neuroleptic drugs, commonly used upon mental patients, do in fact cause irreversible damage to the central nervous system, and are the source of the doctor induced disease of Tardive Dyskinesia, affecting by their own estimate 50 million people throughout the world. In a time when the Government is staging a mammoth and hypocritical war on drugs, there is a vastly profitable coerced market for them, under State auspices.

The medical model and the use of psychiatric drugs and ECT can devalue our experience by doing us physical harm and depriving us of meaning, initiative and well being.

FORCED TREATMENT

Canadian survivor
The mental health business is the only business in the world where the customer is always wrong.

Forced treatment is an important issue to survivors because it involves loss of rights equal only to prisoners. It is the most drastic way our experience can be devalued and interfered with. The stand against forced treatment united the movement in the early days; in fact it was fundamental to it. When a new generation of survivors joined the movement in the 1980's they claimed that forced treatment could be okay. This issue more than any other has divided the movement in recent years and I am somewhat divided within myself as to whether forced treatment can ever be justified.

Journal – On forced treatment

I know that in my own country forced treatment is frequently done too often, for too long, for dubious reasons and without legal advocacy. But I have never had a totally clear standpoint on the issue of whether forced treatment is ever justifiable; just a long line of questions. Can it more easily justified for a few days than for a few years? Can forced treatment ever come under the category of a medical emergency? And how do activists counter the psychiatric establishment's arguments that mad people cannot be informed enough to give

consent? Is forced treatment considered a worse violation than compulsory detention? For me it is.

What alternative ways are there for people to deal with a 'manic' person for example, who buys five houses in an afternoon, something they know the person will regret terribly when they come down? Do the people against all forced treatment think it's plausible for a person to consent to compulsory treatment of their choice before they go crazy again - knowing that when they go crazy again they will not want treatment? How often is involuntary commitment, supposedly done to correct someone's 'psychopathology', or to give families relief or to clean up the streets?

What should you do with a person who is about to jump off a bridge? You know this person is pleased to be alive most of the time and will probably feel this way again soon. But you're not having any luck persuading the person not to jump. Let's say there are no responsive services around to comfort and calm this person. What do you do if the only option to jumping is to have the person locked up? What should be this person's rights and what should be my responsibilities? I continue to be unclear about all this.

Henry (USA)

Some of the people in the part of the movement that is not so strongly against forced treatment are beginning to come around. I always like to say people tend to adopt liberating viewpoints eventually, if they are exposed to them. The thing that convinces people to adopt the viewpoint that forced treatment is wrong, is simply that involuntary treatment doesn't work; it doesn't help people. Programs that are voluntary do work; they are more life affirming.

Forced treatment is one of the parts of the system that is still really entrenched. The majority of the mental health systems still have a long way to go with this. The problem is one of power and people giving up power voluntarily, which rarely happens. Getting the system to give up the power to forcibly treat people is probably going to be the hardest nut to crack of all.

Journal – The debate

The survivor's debate with the American Psychiatric Association achieved very little; as usual the two sides talked past each other. The audience which was mainly survivors was angry. They gave a lashing to the psychiatrists, their absent colleagues and the system they represent. One of the psychiatrists has

written a book called "The Broken Brain". The title drew many hostile remarks. Generally the objections to the psychiatrists' arguments asserted how inhumane psychiatry is. The psychiatrists had to step backwards saying things like 'we know there's a lot wrong with the system'. They were challenged to do something about the wrongs in the system instead of passively colluding with it. Kate Millet continued her slamming speech on the power of psychiatry.

Kate (USA)

The entire power of psychiatry is based upon the commitment law...Lawyers defend persons facing commitment in the tiny space of their utterly routine trials; a procedure whose results can deprive the unfortunate of his rights, even for life. Public defence attorneys actually believe, during the ten moments in which such a fate is decided, that their client is in fact, as incompetent and humanly negligible as the psychiatrist says they are; because he is a doctor and they are not... Scarcely anything is as impressionistic and various as the manner in which human behaviour is assessed. What is crazy to one of us is just funny or silly or cantankerous to another. The thought of losing one's liberty over one's deportment is a terrifying prospect. Yet the person committed stands to lose his or her freedom and every right.

If you break your leg you are dying to have it fixed. You are the party of interest. But in this case, the so called mentally ill person is not the party of interest, someone else is. That someone else is the one who turned them in and stands one way or another to gain by it... Using the family in conjunction with the State, we perpetrate injustice... when a psychiatrist is employed for a fee as an enforcer, capable of summoning the awesome powers of the State; locked buildings, bars, drugs, statutory arrest and re-arrest. We have in fact arrived at a point of large scale surveillance and interference in private life... employing millions, operating through thousands of clinics and offices, accepted now in every institution in our society and even unquestioned in our intellectual frame of reference; congratulated everywhere as a humane form of health.

THERAPY AND ABUSE

I've seen mental health workers abuse people without even blushing when they call it therapy. Someone told me recently that a medical journal recently published an article researching the reasons why psychiatric patients don't like seclusion. The answer is so obvious; who wants to be locked up alone in a small bare room? It's only when seclusion is labelled treatment, with the implication that it is good for you, that mental health workers fail to see its underlying brutality, which would be obvious to them in any non-therapeutic circumstances. Perhaps this is a good standard with which to judge the

actions of mental health workers. If an action causes unacceptable distress in non-therapeutic circumstances how it can ever be justified in a so called therapeutic setting? This standard would leave little, if any, justification for forced treatment.

CAN THE SYSTEM VALUE OUR EXPERIENCE?

Dianne Jennings Walker (Canada)

I walked into a room filled with 45 ex-psychiatric inmates. Upstairs in the same building, proponents of radical therapy were discussing how crazy and frightening we were. While they rationalised the use of restraints... we huddled together and wept and spoke for hours about our pain and loneliness. My search for a better therapeutic model was over.
(In Phoenix Rising, 1980)

When the now condemned lunatic asylums were first built last century they were probably hailed as the most humane option, just as this era's reform, community care is. Mad people who had been subject to the most appalling abuse, physical restraint and neglect were put into the new asylums which were supposed to offer comfort, community, activities, recreation and the and the so called gentler restraint of solitary confinement. But blatant abuses continued despite the new asylum ideology. And the people living in the asylums still did as they were told. They had no choices. The paternalistic, subtle restraints were not even questioned. This was left up to the anti-psychiatry and survivor movements to address over a century later.

Will the reforms of our own era really make life better for survivors? The theory and particularly the practice of community care can still severely limit survivor's rights and choices. Homelessness, mini-institutions, stigma, isolation, exploitation, inactivity and poverty are widespread experiences for survivors in the community. Anyone who promotes community care as the great solution without tackling our society's historical tendency to abuse, neglect and limit the opportunities of mad people is being naive.

The sad reality is that while the mental health system is busy trying to provide better services our communities continues to abdicate their role in our well being. The social service response to this is to rescue us by providing artificial 'as if' replacements to meet our ordinary needs for things like housing, money, intimacy, support and activity. I don't believe for a minute that any service that caters for these ordinary needs can do it as well as willing friends, families, neighbourhoods or business communities. The

mental health system says it wants to provide more and better services. But compared to the average citizen psychiatric survivors are already over-serviced; this erodes our independence, our self-esteem and our rightful place in our communities.

Our experience is devalued by a system which is largely built on the medical model and paternalism, despite the good intentions of many mental health workers. Our society allows a place for common experiences such as falling in love, being religious, having children and so on, but there is virtually no place in the psychiatric system, or elsewhere, for the safe and full expression of the minority experience of madness.

LAST WORDS

The mental health system as we know it cannot value survivors' experiences. In response to this some of us in the survivor movement go so far as to have visions for a culture of madness.

STOPOVER 2
A CULTURE OF MADNESS

Can we survivors put value into our experience?

Kate (USA)

What is at issue, is literally the human mind; its inviolability and sanctity; its grandeur and power; that beautiful spectrum of mental activity that runs the gamut from make believe to calculus, surrealism to logic; the glory of human cognition and the imagination. We grow insecure in our minds, we distrust them which shrinks rather than expands them. We are made uneasy and ashamed, and fear is a very great weapon. It is time to remember intellect and reason, wit and fantasy; it is time to count your marbles. Faith in the human mind is a lot to lose, and nothing that we know of is more precious, more delightful, more liberating.

MADNESS IS A JUDGEMENT

All movements for change search for new knowledge that will liberate people rather than oppress them as the old knowledge does. The new knowledge helps us put value back into our experience. Before I left for my trip I sat down with my journal and tried to unlearn all the things I had been taught about madness.

Journal – On the idea of madness

Very few of us would question the fact that some people have unusual beliefs or extreme emotional experiences. But to go that step further and call these experiences madness is nothing but a judgement. Madness has no real meaning outside the context of our social relationships and how we understand things like productivity, communication, independence and status. Thus, states of mind that are seen to interfere with a person's productivity, communication, independence and status are devalued and become the burden of the 'deviant' minority of mad people.

Once I saw a brilliant television portrayal of the relativity and reversibility of the whole idea of disability. The programme portrayed a 'wheelchair republic' which was designed and controlled by people in wheelchairs. All the ceilings, for instance, were lowered to accommodate seated people. Upstanding people had to stumble and crawl to get around. They had to wear crash helmets to protect themselves from knocking into the ceiling. The programme turned the tables and showed how the people in wheelchairs stigmatised the upstanding people who lived in a world that literally and figuratively cramped their opportunities to be productive, independent and valued members of the community.

To have any kind of disability means more than not quite fitting; people judged to have exceptional abilities don't quite fit into the norm either. People with disabilities are different in a negative way whereas people with exceptional abilities are different in a positive way.

I came to this realisation through my own struggle to find a positive meaning for my extreme mood swings. Now I'm going to add something I wrote in my journal in 1983...

"I have been told again and again that I have a serious problem that needs to be eliminated with expert help. But now, I'm starting to think that my mood swings are not an illness, but a strange and inexplicable minority experience that has been captured, impounded and colonized by the psychocratic regulation of reality. Like colonised indigenous people, I have been denied what is truly mine. The psychocrats with their right knowledge and their power have alienated me from my mood experience. There is no meaning in my madness; it stands outside in the dark, unable to be integrated with my ordinary, socially approved self.

"How different my mood swings would have been if they were judged to be a talent rather than an illness. Or if 99% of the population had extreme mood swings instead of the 1% that do now? Society would be organised around this vast 'normal' labile majority. Perhaps people would even be socialised into experiencing and channelling their mood swings in acceptable ways as other universal attributes like sexuality are. And for the small stable minority maybe there would be a diagnostic category called Mood Inability Disorder (MID) - 'patient is incapable of experiencing the full range of normal adult moods'."

On my trip I hoped to find other survivors who were also trying to unlearn society's stereotype of madness.

THE RIGHT TO BE WHO WE ARE

Ed (Netherlands)

In Holland I talked with Ed in a Utrecht apartment while he gave me his vision of the culture of madness in his slightly halting English.

We should explore a total other direction. My fancy is that it could be a cultural movement where we defend the right to be mad and give some positive attribution to it instead of nurturing the idea that somebody should actually get well again. People have the right to be who they are; they have the right to be mad. If being mad is put on the same level as being black or being a homosexual or being a woman, I think that would be a far better approach; to bring madness out of the back rooms and into the open. Therefore you have to create a culture of mad people. That means that you have to write about it and make films about it and so on.

The thing about being mad is that a lot of mad people don't get well. They are not prepared to or able to act in a normal way. But instead of accepting that fact, people keep going to doctors and believe in all that therapeutic bla-bla, in modern pills and technology. I am sure that in a thousand years there will still be people who are mad, in spite of all the pills and genetic manipulation. I think the biological approach is like a big elephant that comes out of the bush and gives birth to a little mouse.

Psychiatry is wrong in itself, it uses the wrong concepts. The medicine kills people, and people should not be electroshocked. But at the moment our organisation cannot generate a culture of madness. Most people in our organisation believe in normalisation or in fighting psychiatry. They are prisoners of the medical definition of them, and even when they don't believe in psychiatry, they see themselves only as patients who are labelled by psychiatrists - nothing more. That is a very good thing if you only want to fight psychiatry but you are still a prisoner of this fixed relationship.

Journal – In response to Ed

Today while I listened to Ed and Wouter I discovered a point of reference which I've been looking for a long time - the idea of a culture of madness. I think Ed was trying to say a culture of madness can take us beyond the reformist - abolitionist split that has created rifts in the survivor movement in the

Netherlands and elsewhere. A culture of madness gives us the opportunity to create alternatives rather than just repair or destroy the present order.

When he was talking I realised that I'm not deeply interested in psychiatry even though it has impacted on my life enormously and left me powerless and humiliated on occasions. My overwhelming experience of psychiatry has been its inadequacy and its total denial that madness has value and that mad people have the right to determine what that value is. After several years in the psychiatric system I decided it had very little to offer me and started to look elsewhere for answers. Self-help alternatives now interest me far more than psychiatry does. It feels far more creative and effective to generate a culture of madness than to tinker with or smash the culture of sanity and its guardian - psychiatry.

What is a culture of madness? It's anything that places value on madness and raises the status of being mad. Survivor run alternatives do not necessarily do this but I think they always should. Otherwise these alternatives just parody the culture of sanity and defeat their purpose.

There are a lot of issues to explore about how to create genuine culture of madness alternatives. One is the issue of responsibility, paternalism and neglect. Psychiatry has been given the responsibility by society to get rid of madness and hide mad people. For them this responsibility is heavy enough to justify paternalism and the use of force. Another well known historical trend in the treatment of madness has been neglect. Both neglect and paternalism continue because people fear and devalue madness. How then do survivor run services, particularly crisis ones, totally avoid being paternalistic and neglectful? Would there be a concept of diminished responsibility in a culture of madness? Could other people assume some responsibility for the mad person without risking paternalism? The other question we need to ask is - could others leave all responsibility with the mad person without risking neglect?

Another problem with the claim that madness is okay, is that unlike being black or gay, being mad is almost universally perceived to interfere quite drastically with a person's productivity and relationships. It is often a very unpleasant experience even before psychiatry has got hold of it. A culture of madness could be in danger of romanticising madness. It interests me that even the most radical anti-psychiatry people only go so far to say that madness is an okay response, albeit to bad life experiences. So even if madness itself is acceptable its causes are seen as negative and to be avoided. If someone told me my lesbianism was okay but I'm really just a lesbian because of

negative life experiences I would feel insulted and invalidated. Yet the most radical analyses of madness that I know of do not go so far as to say madness is totally okay. I think this is difficult to do when madness is so closely linked to our concepts of disability and distress.

CRAZY AND PROUD OF IT

Henry (USA)

Henry, a larger than life survivor from California gave his more light-hearted vision of a culture of madness in between his famous sneezes which won him the sneezing championship at a recent national survivor conference.

We played at a conference of the Northern California Psychiatric Society. Little did they know that we would play one song I wrote while in the State Hospital called 'Crazy and Proud'? It talks about hating people who read psychology books and the last verse goes:

> *'I won't be a nine to five robot,*
> *well oiled and made of chrome.*
> *I will never have your ulcers*
> *or a split-level home.*
> *You tried so hard to change me,*
> *you bullied and you sneered.*
> *But I will always remain just like I am,*
> *looney, crazy and weird'.*

We invited two psychiatrists to come on stage with us and sing it along with us, without telling them what the song was about. When we got to, 'you bullied and you sneered' I pointed at them and they couldn't handle that.

We in fact sang that song once at a demonstration in front of the American Psychiatric Association back in 1981. And we heard that in one of the plenary sessions of that conference, a psychiatrist got up and referring to our song said 'how are we going to deal with people who are proud of it?' They couldn't figure it out. They thought everybody would want to be cured of it, not proud of it.

LAST WORDS

I was surprised that many of the other survivors I visited did not think in terms of a culture of madness but saw themselves very much in relation to the psychiatric system, even those who were very opposed to it. Repairing or smashing the system alone, will not generate better alternatives. Some utopian vision, however impractical, needs to guide us beyond the present order. This is especially important for survivors who run self-help alternatives; without a strong alternative vision, self-help projects risk parodying the system they were designed to improve on.

Will the survivor movement generate its own culture of madness???

STOPOVER 3
THE SURVIVOR MOVEMENT

What's happening in the movement
in the United States, Britain and the Netherlands?

Suzy (USA)

To me, the truth of a movement is when people who have never heard of each other, from as far away as New Zealand, England and Canada, are thinking the same thing. Then you know that it is true.

PAST PRESENT AND FUTURE

The survivor movement became active in the early '70's in an atmosphere that also produced the civil rights movement, anti-psychiatry, the women's movement and indigenous movements. These causes are linked by the quest for self-determination. The survivor movement has changed in the last 20 or so years; it has grown from a small, unfunded, purist, radical, abolitionist movement to a larger, more diverse and pragmatic movement which focuses on self-help alternatives and reforming the mental health system.

But the movement is not everywhere. It is most developed in the United States and tends to be confined to western style democracies that accommodate liberation politics and the individual pursuit of fulfilment.

UNITED STATES

The survivor movement began in the United States. It has been largely concentrated on the west and east coasts which have also seen the birth of other movements for change. The movement is becoming larger, better funded and more diverse. In recent years there has been a split in the movement. Conservative consumers believe there is a place for mental health services and even for forced treatment. The radical ones who tended to join the movement in the 70's, find this view on forced treatment abhorrent and feel that it negates the whole purpose of the movement, which in a word is liberation.

I talked to some people who have seen changes in the United States movement.

Jenny (USA)

Originally, back in early 1970's when things were first getting started, there were some local groups and a very informal network. There was no money. We had a conference held every year from 1973 to 1985. It was very clearly anti-medical model, anti-commitment and forced drugging; very much in favour of radically changing the mental health system.

In the late 70's two different types of organisations began to emerge: 'lets work with the system' and 'let's not work with the system'. There is a difference between people who see the mental health system as primarily an oppressive system and people who see it as a helpful system that needs a little fixing up. The more conservative groups that were willing to work with the system began to get some funding. A lot of these groups had been brought into existence by the system and its money. They weren't really self-help because they were being told how to do things, they were supervised.

Suzy (USA)

When I became active in the movement in the mid 1970's I suddenly had this feeling of being connected and I was no longer this little lonely person against the big system. It gave me a whole purpose in life, and the very clear feeling that I was going to do something in my life to make sure that what happened to me would not happen to others. At that time in our movement, alternatives and services were very frowned upon. The main emphasis was on political action and picketing and so on.

The movement in the United States has got more popular, which is important. But when you go mainstream you can lose some of the essence of what you were saying. There is a part of our movement now that believes in forced treatment. I can't even conceive of that. To me this belief is not part of our movement. Our movement was based on the idea of total choice.

Henry (USA)

The movement changed tremendously. It has got a lot more broad-based. Up until the early 80's, it was very insular and concerned about being politically correct, not taking Government money, and focused primarily on abuses in the hospitals. It was a fairly upper class movement. I felt alienated by the movement

because I was very concerned with survival issues. I was homeless and living on Welfare.

The movement is now more concerned with what happens to people after they come out of hospital. It is not as politically correct and politically pure any more. The concept of client run self-help programmes has finally gained acceptance. Researchers have decided that what we have been saying for many years is correct; so now there are significant amounts of money are coming in. Our support centre employs 15 people. We provide services for over 120 people a day. Ten years ago that would have been unheard of.

A whole lot has been happening in the field of rights; for example in California, voluntary and involuntary patients have the right to refuse medication because we are beginning to get more and more inroads into the legislative process; we have been able to effectively defeat Bills that decrease our rights and to pass Bills that increase them. I see a time, within the next 50 years when involuntary commitment and treatment will be eliminated entirely and helping systems will be run by those who are being helped. . .the future of our movement is so bright I have to wear shades.

BRITAIN

There are some differences between the movement in Europe and the movement in the United States. Dutch and British survivors for instance, put far more energy into reforming the system than to providing self-help alternatives.

The British anti-psychiatry movement of the 1960's, was not driven by survivors but had a similar ideology, especially to the early abolitionist survivors in the United States. Britain's survivor movement didn't come together until the 1980's. By then the western ideological climate had moderated and the emphasis of the British movement has been on reform. However British survivors I talked to drew a lot of inspiration from R D Laing and others.

Journal – On British survivors

Although I have met some inspiring survivors in Europe, the overall movement here seems to have less clarity and energy than the movement in the United States. British survivors don't seem to have such an expansive vision for self-help alternatives as the Americans do. The British survivors say that under Thatcher, funding for alternative projects has become harder and harder to get. This would abort many self-help alternatives instantly. Surprisingly, few

survivors are actually employed in Britain within the system or to provide self-help alternatives. The national network employs no-one. The ability to employ people can catalyse a movement enormously. Relying solely on voluntary workers who often lack time and resources can put organisations at risk.

Joe (London)

I was involved back in the '60's. The movement then was initiated mainly by Laing. Before that there had been no understanding of so-called mental illness. It was something to be ashamed of. Somehow, the anti-psychiatry movement as well as opposing traditional psychiatry, said a lot about the value of psychiatric experiences to the individuals and the community.

The emphasis then was more on outright hostility to the psychiatric system as it stood, and developing alternatives. We used to advertise telephone numbers and people could contact us instead of going to the doctor. We thought we could do things better outside that system. We thought we could change things. Then I suppose that optimism died away. We started to feel we had to put up with what we've got. The movement now is trying to change the psychiatric system from within, to get better services for people.

Things are getting better in hospital. When I first went into hospital people used to be beaten up by the staff quite regularly. There was no caring idea amongst nurses or guards. Now physical violence against patients is very rare. People who take jobs as nurses actually want to help people. I think the anti-psychiatry and the users' movement has had a big part in bringing this more humane condition about.

One of our great leaps has been to actually have faith in each other, and say yes, we are quite capable ordinary human beings. We have had this particular experience, and this particular experience is not just rubbish; it can actually be of value to ourselves, our own development and to other people's development. That was really a great leap from just being a patient in a Victorian mental hospital.

THE NETHERLANDS

Survivors got organised in the Netherlands very soon after groups began to form in the United States. The movement is more developed here than in other mainland European countries.

Ed (Netherlands)

There were signs of an emerging movement in the Netherlands at the beginning of this century I think. In those days people wrote books and pamphlets about forced admission to psychiatric hospitals. But it got real momentum in the early '70's when Clientenbond started. In the beginning it was a mixture of people but in 1975 there was a decision for closed membership so only people who have been psychiatric patients were eligible.

We don't have a utopia any more. We used to have it in the 70's and the start of the 80's. Many of our campaigns for better facilities, community treatment, and access to files and so on, have been accepted by psychiatry on a formal level. Now psychiatry itself is claiming these slogans. So what is it we want? Will there be no electric shock? That's what we said long ago and why we say it now. Now they say 'we will listen to you'; that's what they didn't say 20 years ago. But they will not do what we ask them to - so what?

LAST WORDS

The survivor movement has three prongs: abolish the system, reform the system and self-help alternatives. Although the emphasis on these vary from country to country and from time to time, I found that the segments of our movement are much more alike than different. The other movement's relationship with the mental health system and other movements also has some universal features.

STOPOVER 4
THE MOVEMENT
AND THE WORLD AROUND IT

How does the survivor movement relate
to the mental health system and other movements?

THE MOVEMENT AND THE MENTAL HEALTH SYSTEM

Henry (USA)

We in the movement have learned to be patient with sane people. We know they are a little slow. All the things that we have been saying for the last 20 years are only beginning to be recognised by the system.

The survivor movement is finding its place in the world. Many of us are still dealing with issues around mental health professionals.

MENTAL HEALTH PROFESSIONALS

When mental health professionals are challenged by the survivor movement, they are being asked to change their relationship with survivors from paternalism to partnership. Many professionals find it difficult to see us as their teachers. When they get over this hurdle they sometimes deny that we are different by relating to us as colleagues.

Henry (USA)

The survivor movement has turned the dominant knowledge of the mental health professionals on its head and the fools have become the teachers.

We would never invite a mental health professional in for a workshop. There is really nothing they can teach us. We teach them.

Virginia (England)

While some survivors in the movement choose not to associate much with mental health professionals many of us try to educate professionals on how to be more survivor-friendly. Virginia shared her approach with me:

I go for their hearts, because I go in there believing that they wish to be doing good, not harm. I am critical but I am also clear that I think the professionals I am speaking to want to provide better services. People don't change when they feel personally attacked; they just defend themselves.

Fiona (England)

Survivors often feel they lack credibility with professionals. But when professionals start to take survivors seriously other problems can appear, particularly when survivors start to provide services. When professionals accept us as colleagues they may expect us to break confidentiality and collude in paternalistic practices. Fiona who worked at a support centre for women came across this problem.

In our self-help service we had quite a lot of contact with professionals. Some would refer their clients to us or ask us if we thought we had anything to offer. Some would also expect us to report back on the client. We would not do that. We totally refused to do that. Occasionally we would talk to professionals on behalf of clients if the clients wanted us to. We reported back in that sense but we would never do it on the professional's instigation which was quite often what they wanted.

Journal – On my relationships with professionals

Today I visited a mental health promotion organisation, particularly a survivor who works there to develop user participation in mental health services. Karen feels isolated, unsupported by most other staff and misunderstood. She feels different from most other staff in a way that can be disempowering for her. Although she had managed to influence some change she told me it was an ongoing uphill struggle though the assistant director has supported her. The assistant director and Karen talked together to me for most of the time.

Initially, I talked to them thinking they were both survivors. I gave them my strong views against professionals becoming members of survivor groups and so on. Then I asked Colette if she was a survivor and she shook her head and

said she was the assistant director. I went red with embarrassment. My thoughts went something like this "She must think I despise her when I didn't mean to create that impression. She will have misunderstood my message and feel very defensive and hostile towards me. What have I done?"

Thinking about this later, it struck me how much I alter my language and emphasis between survivors and professionals, particularly when I'm establishing rapport. Today I used survivor language and emphasis unwittingly when a non-survivor was present. It made us both feel some discomfort. This unintended breach of mine made me realise how much I have filtered my messages to professionals to rescue them from their guilt and defensiveness, so that I do not have to go through the discomfort of feeling responsible for their discomfort. Triggering off people's guilt and defensiveness usually paralyses them or makes them hostile. But I don't want to feel responsible for the moral discomfort of mental health professionals, or to puff their pillows and feed them bland messages. Why don't I just say exactly what I mean?

I was brought up with a strong liberal middle class ethic of tolerance. Then I got quite a shock to realise many people are less tolerant than me, and that for some tolerance is a luxury. It's so easy to be tolerant when you're not oppressed or even when you've denied your oppression. I don't think I've ever totally asked myself - why should I tolerate mentalists, sexists and homophobes for not tolerating me? Instead I've told myself that I need to try and understand these people's points of view.

As a leader in the survivor movement in New Zealand my ethic of tolerance, I'm sure, has helped to shape the style we use to relate to mental health professionals. In Auckland we have not been particularly confrontational. We need to get more stroppy and radical. Too much tolerance will stop this from happening. I don't totally reject the ethic of tolerance at all. I just think we need to think about when it's good to be tolerant and when it's not.

Brendan (USA)

During my trip I talked to several survivors who had also been mental health professionals. Some of them were in the difficult position of being rejected by their professional colleagues for being survivors and being treated with suspicion by other survivors for being mental health professionals. Brendan had worked for several years as a clinical psychologist while he was receiving treatment for his mood swings. I talked to him soon after he started working

for a survivor organisation; his co-workers there were wary of him but he was more bothered by the anti-survivor attitudes of his professional colleagues.

The staff in mental health centres are not supposed to talk about their problems, ever. You are in jeopardy of losing your job if you let it be known that you are receiving mental health services.

I have found out that everything that the consumer movement espouses are the things that I always believed in as a therapist but never found in the system. I had a rude awakening after I went to work. Firstly, I found that most of the people who are working in the system are rescuers, not genuine helpers. And the second thing I found is that you can't understand someone until you have walked a mile in their moccasins.

I got in a lot of trouble at different agencies that I worked in, for advocating for different treatments and for respect of people. When I went to staff meetings for instance, I would be horrified at the negative emotional atmosphere - the patient bashing, the jokes and the insulting remarks. I tried to get people to ask themselves how they would like to be talked about like that. For the most part I wasn't very successful in changing anything. It was very very depressing.

THE MOVEMENT AND OTHER MOVEMENTS

Although we have a lot in common with other movements there are things that separate us from them. We have our opponents as well as our allies. Our most troubled relationship, aside from mental health professionals, is with the movement of the families of the 'mentally ill'.

FAMILY ORGANISATIONS

Jenny (USA)

The family organisations are more psychiatric than the psychiatrists.

Survivor organisations usually have a tense relationship with mental health organisations run by families. A lot of survivors believe their families have contributed to their distress whereas family members tend to alleviate their guilt feelings through finding favour with genetic and biochemical theories of 'mental illness'. Like mental health professionals, families tend to be

pessimistic and paternalistic towards survivors. To add fuel to this volatile mix is the issue of forced treatment and detention. Family organisations lobby to make it easier to commit people which survivor groups find offensive.

Jenny (USA)

Jenny gave a tired sigh when I asked her about her experience with family organisations.

The family movement in the United States has grown fast and has so much credibility because they are middle-class respectable people and they are not mentally ill. The family movement puts total reliance in the medical model, particularly genetics. There is this new drug out and they're volunteering their kids who are usually mature adults, to try it out. On an individual level I can understand families have been through a lot and suffered a lot and have their own issues. But I wish they would stay organised as a support group around their issues but they don't. They see themselves as representing the consumers because "we speak for people who can't speak for themselves".

Henry (USA)

Henry had some positive things to say about family organisations; they meet with survivors on some issues at least.

We have had an interesting relationship with the national family organisation. They've introduced legislation to expand involuntary commitment and we've opposed them in almost every state. On the other hand, when we are dealing with income issues, housing issues or discrimination issues we are really together. They have also been very supportive of self-help programs. The same family organisation person who I've been known to call fascist in the middle of a meeting, is on our mental health advisory board and has consistently voted in favour of our centre.

THE WOMEN'S MOVEMENT

Jenny (Massachusetts)

The women's movement has not been terribly receptive to ex-patients; there are an awful lot of therapists in the women's movement.

I wanted to find out about any feminist survivor projects; there are very few of them which have always surprised me. I listened to Fiona and Virginia talk about their unhappy experiences with a women's survivor network in Britain. I wrote down my thoughts about what they said on a crowded Easter train to Nottingham. Beside me stood a loud young man who cupped his hand suggestively around his girlfriend's buttock.

Journal – On the women's and survivor movements

Several years ago a women's survivor network was set up by a woman who has never used psychiatric services. This woman called herself a survivor. The group decided that a survivor was self-defined which meant any women who called themselves as survivors could join. But members of the women's network started to feel alienated by the fact that their leader had never sampled psychiatric services. She was a trained professional who had arranged for her colleagues to be on the management group.

So the network was run by a group of tired, busy mental health workers who were not familiar with survivor consciousness or the day to day realities of the organisation. The professional management group did ask survivors to join them but their whole style and language had already alienated the survivors who never really participated. This reinforces my view that professionals should have as little to do with the formation and maintenance of survivor groups as possible.

Another intriguing aspect of the women's network is its allegiance to two movements; feminism and the survivor movement. I asked two former network members if these two allegiances ever came into conflict or if one overrode the other. They suggested that the network's survivor allegiance was compromised by the professionals who identified much more with the women's movement. This bias is implicitly maintained in the membership criteria; it is absolutely essential to be a woman but it is not essential to be a genuine survivor. To be part of the network it was more important to be a woman than a survivor.

Both the women's and survivor movements share the same liberation roots and have far reaching similarities. For this reason it has always intrigued me that virtually no women survivor initiatives have developed anywhere. Perhaps the impetus for survivor women and feminists to combine is not so compelling. While survivor men are never oppressed for being male they are oppressed for being mad and they share this oppression with survivor women. Men and women have much more common ground in the survivor movement than they

do in the women's movement. On the other hand many feminists have more common ground with the helping professions than survivors do.

Even though survivors and feminists can exist happily side by side contradictions occurred in the women's network when they were blended together. The loss of faith in professionalism and therapy are central to survivor ideology and only peripheral to feminist ideology. Feminist mental health workers cannot be relied on to give credibility to our differences in ideological orientation; some do not even recognise them. White women have begun to recognise their role in the white oppression of black women. Professional feminists need to recognise their role in the oppression of survivors. Being white or professional gives you power over others whether you are a woman or not.

Hilary (England)

Later I talked with Hilary, a feminist, who as a survivor felt much unsupported by other feminists. She waited for me three stories up in an old grey British tenement building while I got lost in the London traffic.

I've found that the survivor movement has got a lukewarm response from the women's movement. Women survivors tend to identify as survivors first, so women only initiatives are unusual. I did benefit from the women's movement but if I had encountered the consumer movement first I would have benefited from that more. The women's movement did not validate my experience as a survivor.

ETHNIC MOVEMENTS

It disappoints me that people in oppressed groups can ignore the experience of another oppressed group. Hilary's invisibility as a survivor within the women's movement is just one example I have seen. In my own country Maori mental health workers or activists are sometimes less sensitised to the powerlessness of survivors than Pakeha workers are. I've seen the same pattern with Black workers and activists in Britain. Perhaps the racism they are fighting is so huge that they have no room to fight for anything else.

Jenny (USA)

Ethnic minority mental health professionals are very up on their own issues, but they're not always sensitised to survivor issues. A lot of minority professionals think black in every other area of their life, but in mental health they think white.

OTHER DISABILITTY GROUPS

People from other disability groups are also organising in the countries I visited. Their issues are similar to ours but so far we have not formed a strong alliance. This probably should happen.

Jenny (USA)

People with physical disabilities are also oppressed by a medical model. If you are blind or deaf you are not sick; and yet people always assume that you need a doctor. But primarily you need advocacy and peer assistance and things like that. So a lot of the problems between disability groups are very similar. Physically disabled people have a lot of experiences with others seeing them as infantile and unable to do things just because they are disabled. Once you can overcome the stereotyping that goes both ways, there is a tremendously good meeting of the minds.

LAST WORDS

I have found that different movements, although based on comparable experience and principles, can often misunderstand and oppress each other. The survivor movement will always be in a state of tension with the mental health system and family organisations. Much of our energy is focused on changing the mental health system in ways that it does not want to change. this process can be referred to as political action or activism.

STOPOVER 5
ACTIVISM

How does the movement
try to change the mental health system?

How can activism be better integrated with self-help?

ACTIVITIES FOR CHANGE

The survivor movement exists for one purpose which is change. All our
activities are motivated by our desire to change ourselves or the things that
limit us. Roughly speaking our activities fall into two groups -
self-help and activism. Support or self-help activities enable us to change
ourselves.

Activism describes the means by which we try to change society and the
mental health system to give us improved rights and quality of life. Activists
could be anything from abolitionist terrorists (I haven't heard of any yet) to
token consumers on a mental health committee. I'm using the term to cover
the whole abolitionist-reform spectrum of the movement. The issue of
activism will be covered in this chapter. The main focus of my trip, self-help,
will be the subject of all subsequent chapters.

THE PROTEST MOVEMENT

Protest was common in the early days of the movement but these days
survivor activists are far more likely to pick up their committee papers than a
placard. In New York I made contact with a group which had just formed a
national coalition of survivors and others to promote radical change. They
feel the movement has veered away from political action with the influx of
conservative consumers over the past few years. I saw the new group in
action.

Journal – On an anti-shock protest

I went to an antishock protest outside the New York Hilton where the American
Psychiatric Association was meeting. The most creative effort was a head

costume of broken eggshells worn by a woman who held a placard saying 'I'd rather be cracked than fried'.

Only about 20 protesters turned up. It reminded me of a 70's demonstration. Some of the men had long hair in pony tails. Most were in their 30's and 40's and looked like experienced protesters who had aged but otherwise changed little. They held banners and chanted "Stop Shock" to the psychiatrists walking by. Then they joined hands in a circle and gave personal shock testimonies through the megaphone which they passed around. Then they sang "We Shall Not be Moved". I didn't feel comfortable with the style of the protest which I found anachronistic.

SURVIVOR PARTICIPATION IN THE SERVICES

Bob (England)

I had a meeting with the medical superintendent to discuss the volunteer's expenses. The first thing he greeted me with was "Oh yes, you are one of Dr H's patients aren't you?"

I only visited a small handful of services and non-survivor organisations that were attempting survivor participation but I did talk with many survivors about their experiences with survivor participation.

Survivor participation in the services implies reform rather than abolition. It has become more common over the last decade. Mental health workers are beginning to realise that consumers have the right to determine the kind of services they want. Unfortunately, survivor participation is easier to think about than do.

EXPERIENCES OF TOKENISM

Survivor participation is a bit like biculturalism in my own country -between the indigenous and colonising populations. The colonisers, and their parallel the mental health workers, often think the process of participation or partnership is going better than the disadvantaged group who typically feel it is tokenistic.

Bob (England)

Some survivors are too afraid to give their views in front of mental health workers even when meetings are set up for this purpose. I have also experienced a reluctance to talk in front of hospital staff. Bob from Nottingham recalled his experience emphatically.

Resident only meetings with no members of staff present, are where it all comes out, because the classic syndrome in any institution is that the residents will talk more about their wants and fears and hates, among themselves than they will in front of the staff. At a resident only you can sit down and say "I think the grub is shitty" but at a mixed meeting you just sort of shrivel back.

Often survivors feel their involvement is tokenistic and makes no real changes. Bob commented on how little power survivors in hospital have, even when they organise.

It is okay for us to say what we want but if nobody is prepared to listen we might as well talk to the wall. I can't go around and say to the catering manager "you're sacked because you are not producing the right sort of menu". Even with the aid of a very sympathetic unit general manager, it took about six months to get a bath plug, and 18 months to get a proper tea trolley for ourselves.

Judith (London)

Do mental health workers really want to deal with survivors who are angry or do they prefer someone nice and well behaved to come to their meetings? Do they really want to change? Why do they frequently forget that we exist? Judith talked about the situation in Britain

I have to keep reminding them we are here. I think they are beginning to know we are here now; we have better publicity and are better organised. Users go to the organisation's Annual Conference but always find it an unfriendly event. It's kind of us and them; the professionals are being paid to be there, but the users are on benefits and can't afford to live.

Laura (USA)

Laura from the United States has had similar experiences to Judith.

We have designated some people to work with the mental health department and other groups involved with mental health. We've tried to set up joint committees with mental health workers and organisations to work on common issues. But it takes initiative on our part to be included. When they're setting up conferences or establishing committees, they often don't think to include us.

PARTICIPATION IN A LARGE ORGANISATION

One of the organisations I visited wanted more survivor input so they employed a survivor, gave her an office and a salary and told her to get on with it. Being the sole representative of a disempowered group in a powerful organisation can be a lonely and disempowering experience.

Journal – On the importance of peer support

Our first visit in Britain was to a national mental health promotion organisation. They have employed a woman, Judith, to network with British survivors and to influence the organisation's policies. The consumer network hasn't made much of a dent in the organisation's policy yet but it is helping to get survivors moving in parts of the country. Judith produces a newsletter which is distributed widely. And she coordinates the regional survivor committees that feed back to the main organisation. Judith seems to have a difficult time as the only survivor employee at the national office. There are no other available survivors to support her there. She feels isolated, overlooked and sometimes over- controlled by other staff. I didn't envy her in this situation at all.

This visit made me reflect on the two survivor participation workers who have been employed to network and feed into policy making in Auckland's central district mental health management. Initially the workers were to be just supervised by Psychiatric Survivors. Then the district manager rang one day and asked Psychiatric Survivors to administer their salaries to avoid any conflict of interest. Psychiatric Survivors wrote out a job description, advertised the job and selected the workers and now pays their salaries. They are also based at Psychiatric Survivors though they do have office space at the central district headquarters.

Surely Judith would be happier and more effective if she was in more of a contractual relationship with the mental health promotion organisation, with

day to day access to other survivors and the power of an effective survivor group behind her.

UNTAPPED SURVIVAL POTENTIAL

My next visit was to Robin Hood country where there has been a lot of survivor activity in the last few years. In Nottingham I saw a good example of well meaning professionals standing in the way of survivor participation. But my biggest lesson was the realisation that paid or experienced survivors can also stand in the way, or at least fail to facilitate participation among their more disempowered peers.

Journal – On a meeting that didn't draw potential

Craig took us to a meeting he had organised in a day hospital. The purpose of the meeting was to form a group to increase consumer participation in the day hospital. Two professionals and eight to ten users were there. Craig opened the meeting but did very little active facilitation after that. The professionals talked a lot at first about some of their frustrations trying to change things, and how users need to get together and become a strong voice. Then some users voiced some complaints which they clearly expected the professionals in the service to find solutions for. The two most vocal women came across as very powerless and negative.

None of the users there had caught on to their own potential to improve the service and their lives. It became clear to me that until this realisation happened they would never make an effective action group. Why wasn't this happening?

Firstly, the involvement of the professionals. They were both very aware young men who were committed to empowering users. One of them took the minutes and the other offered to send out a notice for the next meeting. They were reluctant to do these jobs but none of the users came forward. In spite of their political correctness their presence at the meeting reinforced the user's feelings of uselessness and dependence. And it's very likely that the users didn't share some things because the professionals were there.

Secondly, Craig who facilitated didn't offer them an alternative vision or messages that the users were strong and able to participate in the service.

I would have preferred the following to happen. A user only meeting, perhaps off the premises, and totally organised by the survivor organisation. The aim of the group would be initially to repair the self-image of its members and educate them about issues so that they can form an effective action group. The facilitator's first job would be to share their own experience and create a positive role model. They would need to use every opportunity to introduce ideas and to communicate their confidence in the group to do its tasks. Members would need to feel free to share their own experiences and ideas. Members would also be asked to take on some responsibilities like taking minutes or advertising meetings or facilitating future meetings.

The paid user worker would not become another professional because they would share their similar experiences, believe in the capabilities of the group and back this up with shared responsibilities and collectively made rules. The worker would encourage the group to be clear and consistent in what they do, as well as how and why they are doing it. Finally, the worker would work towards her own redundancy in that particular group.

After experiencing the rewards of facilitating a self-help organisation, survivor participation hardly excites me. When two groups as different as survivors and their paid 'helpers' get together difficulties are inevitable. Stereotypes have to be shed and new approaches have to be found. I have yet to see an example of survivor participation that inspires me.

ACTIVISM AND SELF-HELP

John (USA)

We need to create ways of working together that nurture us as individuals but also leads us to actively try and make things better for all of us. I don't think we are quite there yet as a movement. The politicals are doing political stuff; they usually burn themselves out and aren't very nurturing to each other. Then we have the self-helpers; all they do is go to their meetings and become meetingites. Is there some in between?

THE PERSONAL MEETS THE POLITICAL

My travels showed me how important it is for the survivor movement to work on both the personal and the political fronts. Support without activism

denies people access to the larger issues which have a profound effect on their lives. Activism without support risks us getting out of touch with the grass roots which we represent and from which we come.

Journal – On the role of self-help in activism

The thing that makes the self-help approach so powerful is that it starts with the self, with our own pain and our own resources. This enables us to assist others in similar situations. Action only groups, if they're not the survivors' primary group, don't take people back to their selves. Some people who come to user groups have done a lot of healing elsewhere. But many haven't; these are the ones who need the foundation of support the most. Action groups are specialised; most members of an organisation such as Psychiatric Survivors will never want to be in one. But I believe an action group is better supported and informed if it is attached to an organisation that has a foundation of support. All the workers at Psychiatric Survivors try to have regular contact with the support groups to keep us in touch with our survivor heritage and to guide our work.

Most groups that start as action groups face the problem of catering for the majority of people who come along to have their immediate needs met. In the first year of Psychiatric Survivors most people said they didn't want an action meeting. Even after trying to alternate action meetings and support meetings, the action component continued to get smaller. Psychiatric Survivors is still weak when it comes to political action. But I don't regret going with the flow of the group. Since then I've realised that any thriving survivor group must be built on a foundation of support. People's immediate needs must be met before they can address the wider issues.

Jenny (USA)

In our drop-in center I see a lot of people growing towards activism. But some of the people's needs right now are really basic; we have a lot of homeless people who are hungry. If you are hungry, don't tell me about liberation, tell me about food. It is really important that we don't require people to do action work; people can just see this place as a social centre. They define what their need is.

WHEN THE PERSONAL IS MISSING

Pythia (Netherlands)

The chairperson of a Netherlands action organisation felt that it lacks a support base. She said survivors need to make sense of their own experience and share this with other survivors to gain strength and solidarity. Support meetings tend to build more confidence and unity than any purely business meeting could.

The people who work here do not talk too much of their own experience, and that is not a good thing. We have to have a foundation of support in our organisation. We need to get clear in our own minds about our experience and what we can do with it.

Ed and Wouter from the same activist organisation were disillusioned with the lack of political progress they had made over the last 20 years. Concentrating almost entirely on political issues can be a draining experience.

Wouter

Someone said "if you look at psychiatry as a building, the Clientenbond is only pissing against it". We are not effective.

Ed

I disagree. Two years ago a big monument in Amsterdam had to have to have a lot of work done on it because it had been pissed against for years. It was eroded, the foundation was crumbling.

Wouter

That is very funny but it is out of place. You cannot claim that psychiatry has become weaker or dissolved over the last 20 years.

CONSCIOUSNESS RAISING

'The personal is the political' is a saying coined by the women's movement which enables support and activism to belong together. Consciousness raising is a self-help process that helps us understand our personal realities in the political context of oppression. People don't talk about consciousness

raising much these days; it was a popular term in the women's movement and among radical survivors in the 1970's. But the process must happen in any movement, whether it's called consciousness raising or not. Perhaps it's not happening consciously enough in the survivor movement of the 1990's.

I used to fear that consciousness raising merely pushed people from their conservative orthodoxies into more radical orthodoxies. But during my trip I made some shifts in my thinking which changed my mind.

Journal – On consciousness raising

Since I've been travelling I've been thinking about ways to deal with members whose beliefs contradict the philosophy of the group. In Psychiatric Survivors there has been a wide spectrum of beliefs of issues like committal, ECT, drugs, the usefulness or otherwise of mental health workers and so on. I have never consciously attempted to influence any of these beliefs, thinking that the organisation should be able to accommodate a variety of viewpoints. Over my life, in less influential positions than I am in now, I've developed an aversion for orthodoxies. In my leadership role I have wanted to minimise orthodoxy as much as possible so that members are free to believe what they want without weakening their claim to membership.

But in the United States I watched some meetings where the leader was 'raising the consciousness' of the grass roots membership. I found that the leaders kept the members informed on issues and encouraged discussion on them. They were clear about where they stood without pushing it. They related the personal to the political and worked on self-image and self-help as much as the external aspects of oppression. I felt quite comfortable with their style and I think the members did too.

The assumption behind consciousness raising is that our oppressors fill our minds with false knowledge which is designed to maintain our oppression. We can break away from this by creating alternative knowledge which reflects and defines our true selves rather than an imposed role. I used to think that individuals should be left alone to make whatever changes made sense to them. But now I see more clearly that there are distinct patterns in people's journeys from oppression to freedom, whether they are in London, San Francisco or Auckland, whether they are in the women's movement, black liberation or the survivor movement.
Consciousness raising can facilitate and support that journey; it doesn't have to impose it. I've now realised that inside a movement people's consciousness tends to develop in quite predictable ways. My own for instance.

Ten years ago I was fatalistic and dependent on the services. I thought my condition had condemned me to a semi-productive life. I thought that drugs were the only way to deal with my mood swings. I didn't question any of this.

Five years ago I had begun to ask myself why my mood swings were regarded as an illness. Though I was on mood drugs I realised I was living as well as I could with my mood swings, I had learnt how to protect myself when they approached and to live to the full when they subsided. I was quite certain that my mood swings had a physical cause and that I was completely powerless to stop them. I thought psychiatry was limited and quite useless but not particularly oppressive. I was not clear about any alternatives.

Now, I am much clearer about alternatives. I think psychiatry is on balance bad for people's mental health. I am looking for the possible role of oppressive life experiences as causes of my mood swings. Although drugs stabilised my mood swings I am looking for alternative ways of stabilising them which involve me as an active participant and give my mood swings the meaning that has always been denied them.

There is no way that my journey could have gone in the opposite direction, from my current position to my initial position ten years ago. The idea is absurd and this strengthens my conviction that people in the movement grow according a pattern. Some people may not grow very far or they may have spurts in some areas but not in others. But they are growing in the same direction. It's taken me a long time to realise all this. Some stakes and fertiliser in the form of consciousness raising could be a good thing.

Last word

The activism of the movement has changed from the abolitionist protest movement of the early 1970's to the more mainstream reformist survivor participation of the 1980's and beyond. One of the biggest challenges of today's movement is to integrate activism with self-help which is the focus of the remaining chapters.

STOPOVER 6
SELF-HELP

What is self-help?
How does it compare with conventional services?

Laura (USA)

Self-help made a huge difference to my life because I was really entrenched in the mental health system; I sat around for years in board and care watching TV and doing nothing. Self-help was a positive alternative for me. It gave me another way of dealing with my problems and it helped me get out of the system.

SELF-HELP AND CONVENTIONAL SERVICES

A self-help alternative can be anything from a support group, a theatre group, a drop-in centre, a housing project or even a small business. Conventional mental health services provide many of these things too. In self-help it's not so much what you do, but how you do it that makes the difference. The 'how' is really the essence of self-help.

Self-help alternatives have arisen because the conventional services haven't delivered what people are looking for. Sally from California told me that homeless 'treatment resistant' survivors in her area wouldn't go near the conventional services but were happy to go to the local survivor run drop-in.

Why are self-help alternatives the only place some survivors would go to? What makes them so different from conventional services? It's crucially important that people understand the difference. I've collated a few definitions of self-help and contrasted them with conventional mental health services.

SELF-HELP ALTERNATIVES   MENTAL HEALTH SERVICES

Grass roots	**Bureaucratic**
Community groups	Large organisations
Self-governing	**Remotely Governed**
Group makes decisions independently of outside control	Service unit often has decisions imposed from elsewhere in system
Participatory	**Hierarchical**
Members have equal decision making powers & flexible roles	Clients have few decision making powers & cannot change roles
Mutual support	**Clinical judgements**
With peers is most valued behaviour	From experts is most valued behaviour
Choice	**Removal of symptoms**
Has paramount value so coercion not justifiable	Has paramount value so coercion can be justified
Optimism	**Pessimism**
About peers is high	About clients is rife

Well, where would you rather be? The self-help alternative may look wonderful on paper but one of the most important things I learnt on my trip is that self-help alternatives are extremely hard to achieve. More about this follows. Firstly I want to share with you some of the many positive things people told me about their encounters with self-help.

Fiona (England)

Some survivors made important comparisons between self-help and the services. Fiona echoed my own experiences with group therapy. Like her I have sat in circles of distressed people who looked to calm and controlled therapists for answers and approval.

In a psychotherapy group the therapist is always seen to be more together than everybody else, even if they are not. You immediately lose an equal relationship. To me one of the basic principles in self-help is that you are all equal, you are all there in the same place. A psychotherapy group can't be self-help.

Brendan (USA)

Brendan talked about the way the system intervenes and contrasted this with the way peers accept each other in self-help groups. His comments reminded me of the painful message I got from some mental health workers that I while I continued to have mood swings I was unacceptable.

A professional system by definition thinks the people coming to them are unacceptable in some way; the purpose of their existence is to change people, whereas when you go to a self-help group there is no pressure for change. Self-help groups give people a sense of empowerment. Instead of feeling like a passive victim of the world, you start viewing yourself as in charge of your life. It is a very different experience to call a friend in the middle of the night when you are suicidal, than to call a crisis intervention team. Your friends will listen to you and support you through it but it is very likely that the crisis team will shove you in hospital.

SELF-HELP AT ITS BEST

The most impressive self-help alternative I visited was a drop-in centre in New England. This was my last stop; I was tired and ready for home. But in their gloomy suburban basement I was still able to absorb some important lessons about the difference between self-help and conventional services.

Journal – On drop-in centre

I visited a neighbourhood drop-in centre for survivors. Everyone who goes is considered a member. Fifteen or so of the members work half a day per week for US $75 per month for at least 16 hours work. The paid members are chosen by the membership. They need to have been involved with the centre and shown some commitment to it. All policy and expenditure decisions are made at the weekly business meeting which all members are entitled to attend. The paid members have no more formal decision making powers than other members though they are likely to have a lot of influence. The centre has no co-ordinator, though Jenny who is the projects co-ordinator most closely approximates this role. Her presence at the centre is very part time. She goes to the weekly business meeting and was an obvious leader at the one I sat in on. However, she told me some of her ideas have not been taken up by the group. She's very committed to this kind of democratic decision making.

The paid members usually work in shifts of three. They unlock, make the coffee, empty ashtrays, clean up and so on. They're also expected to ensure the centre's rules are adhered to and to deal with arguments and other crises. All members are encouraged to initiate new activities at the centre such as meditation, outings, finding cheap tickets for movies, crafts . . . and so on. Some are politically active. Apart from the duties of the paid members, no one is pressured to do anything.

The business meeting I sat in on was fairly chaotic. The chairperson wandered off and there was a lot of unstructured discussion. A lot of negative and positive feelings were expressed from feelings of threat and anger at someone's comments, to appreciation at the work some members had done. The centre has about 60 members; it would only hold about 20 at one time. This is small enough to have almost total democracy and I'm convinced it's the best way to run a drop-in. From the moment a new survivor walks in the door they can use and develop their initiative and decision making powers which are likely to have been stripped by the mental health system, and urgently need to be built up again.

The drop-in at Psychiatric Survivors in Auckland does not compare well to this one. The distinction between paid and unpaid people is greater at Psychiatric Survivors. Less people work for more hours per week than at the New England centre. This has several implications. Firstly, fewer people have the opportunity to take on paid responsibilities. The people who are paid at Psychiatric Survivors spend all their time at the drop-in as paid workers and do not merge back into the general membership. They are very clearly identified as workers, and as part of the decision making group. The drop-in workers, who do it for 20-30 hours per week each, complain of boredom often. More workers working less hours could solve this problem.

Decisions about the Psychiatric Survivors drop-in are made by the decision making group, which only has input from the workers. I feel strongly that the Psychiatric Survivors drop-in, needs to become a fairly autonomous unit which makes its own rules, activities, expenditure decisions and chooses its own workers, all within broad self-help parameters set by the decision making group and the wider membership. The decision making group and the drop-in could be in a negotiating relationship re funding and other resources, which could then be distributed by the decision making group.

The drop-in would choose its own representatives to be on the decision making group, who would report back its business to the drop-in business meetings.

This would empower drop-in members. The paid members would not be called 'workers' or 'volunteers' as they are now, because these terms accentuate differences more than 'paid members' and 'unpaid members' do.

I can see now that the drop-in at Psychiatric Survivors is not a true self-help alternative. The workers there are virtually in the role of babysitters while the people who come along sit passively in a setting that is not so different from the hospital or day centre lounge.

THE DIVERSITY OF SELF-HELP

 Alcoholics Anonymous, which some say is the original self-help alternative, differs slightly from contemporary self-help philosophy.

Journal

The other night I went to an AA meeting in Bristol with Virginia who is a survivor and a member. The meeting was a sharing session which was started off by a member who talked for about 30 minutes. Then other members responded briefly with their own experiences. The meeting lasted for just over an hour. At the start there was a reading and a few quotes were stuck on the wall. The AA prayer concluded the meeting.

The people who spoke got straight to the heart of their shared problem. I want to look more closely at AA and other "12 Step" programmes to see what we can use. There has been some criticism of this approach. Critics say that it focuses too much on the individual and ignores outside stressors such as poor relationships, poverty, unemployment and so on. People are encouraged to see the source of their distress as within themselves. Then they will be able to 'reform' themselves because they are not relying on outside factors to do it for them. I agree with this to some degree.

But at the meeting, which I was generally very impressed with, some of the speakers talked themselves down with comments about being self centered or having over large egos. I felt uncomfortable with this and I recalled another "12 Step" group GROW which is targeted at psychiatric survivors. GROW's starting statement is "I admit that I am inadequate and maladjusted". I can't see how real self-help can begin with such a self-damning statement. I talked to Viv about this and she understood my point but didn't think it interfered

with people's progress in AA. She encouraged me to find out more about AA and this doubt of mine might fall into place.

Last word

Self-help is a way of organising that returns power and competence to individuals in contrast to the mental health system which takes power and competence away from people. However during my trip I found that some self-help projects were starting to look like conventional services. . .

STOPOVER 7
SELF-HELP ORGANISATIONS

How do we maintain our self-help principles and at the same time most effectively manage our organisations?

MANAGEMENT

Aspirations to both genuine self-help and good management can be loaded with contradictions. For me, the big challenge is to allow room for both.

The problem is that self-help alternatives do not find an adequate role model in mainstream organisations. Many of us get lost in the gulf between our experience of mainstream society and our vision for self-help alternatives. We feel that mainstream organisations like schools and mental health services are often hierarchical, authoritarian and place value on conformity and efficiency. We don't want these features creeping into our alternatives but we're not always clear about what we do want. Which elements of mainstream organisations should we throw away? Which elements should we adapt for our alternatives? I've been looking for answers to these questions for a long time.

Many survivor groups in the early stages focus on their ideals and tasks. The need for management can catch us unawares. In my own group messages were getting lost, the auditor was tearing his hair out and one of the workers did things the others didn't agree with. At that point we realised the need for the management of information, people and finances within our group. None of us had ever done this before.

DIFFERING APPROACHES TO MANAGEMENT

The largest survivor organisation I visited predictably had the most developed management structure. I wanted to find how much their management resembled mainstream organisations and if their organisational sophistication had diluted their self-help principles.

Lynette (USA)

Consumers are becoming more aware of the need to maintain and administer consumer organisations. Its part of the evolution of what we are doing. First of all we were in a little boat that was sailing smoothly when all of a sudden the waves started rocking us. We now see a need to develop leadership. People get burnt out. Each of us is not in this forever and ever. More people need to join. Issues around recruitment, staff development, fundraising and things like that are a real struggle to us.

John (USA)

Lynette's leader, John talked to me over his enormous cluttered desk about the importance of good management.

Our organisation has expanded. We do the job in an extremely responsible and well managed way. We go out aggressively and compete to get grants. A lot of consumers get funding and screw up because they don't have management competency. Nobody wants to give them any more money. They stay small or go under. I often see groups who approach the question of organising in a very anarchistic manner; everybody puts their own two cents worth in and they end up with a mish-mash. At a certain point the group will has to be gelled and the individuals in it have to go along with that. To discuss and debate is good, but at some point you have to say "these are the things we are going to accomplish" Then you have a clear mission and a clear vision. That's the only way funding sources ultimately fund you.

Laura (USA)

Compare John's attitudes to Laura's who believes that the bureaucrats who hold the funds unreasonably expect self-help groups to be managed like mainstream organisations.

The bureaucrats don't understand how self-help groups work. Because some of the fundamental principles of self-help are non-hierarchical, we do collective decision making which takes a lot of time, and we don't designate one or two people to be in charge, it's everyone's responsibility. We had a contract with the federal government. They wanted one person to be accountable and they kept recommending that our network have an executive director. They also required written personnel policies, and they wanted detailed accounting, an audit, those sorts of things that as a client group we don't have.

John would probably disapprove of Laura's network because it is less efficient and pragmatic than his own. To me John's organisation resembled mainstream organisations too much but on the other hand I had some reservations about the lax management of Laura's network.

Journal – On insufficient management

I met with a State wide survivor network today. This network is similar to what the Aotearoa Network intends to be. They lobby, facilitate consumer initiatives, encourage client participation in services etc. In some ways they have been a really effective organisation but several things appear to have caused the network some problems.

They have a board of directors consisting of 17 survivors around the state; their constitution allows them up to 30 on the board. I think this is too many. I can't imagine an effective decision making group beyond about ten people. On top of this the board of directors never meets in person but make their decisions through teleconferences. These are not like usual meetings. The order of speakers is determined by the chairperson beforehand. If you've spoken and you want to say more you have to ask to be put on the list again - at the bottom. It sounds like there's not much room for spontaneous comments or creative ideas to emerge. The participants also do not have the chance to get to know each other, find rapport or discuss other issues. Some members of the network's board have never met each other.

Laura told us that board members were elected according to how politically radical they are - expertise in administration and finance is not regarded as important for the board. So the board is full of politicised people who take little interest in the running of the network. There does not seem to be a clear leader or leaders in the network to bring the different factions closer together. The network has not had a major grant renewed because it did not have a personnel policy or book-keeping system in place, which was a requirement for this particular grant. The office has been reduced to one administrator who seems to have very little support. There is no co-ordinator. Some people do part time work for the network, often based in other parts of the State.

One of the worst consequences of the lax administration and undelegated powers of the board has been the two law suits that have been brought against the network. In the United States options for dealing with disputes veer in the direction of the courts. In the first case the network made a handshake agreement with someone to make a video. Without investigating the possible

consequences of their action the network terminated the contract because of the man's unsatisfactory work. He claims the network acted outside the law and is bringing a law suit against them.

As well as this, two network employees had their pay cut off after they refused to leave their employment with the network. Apparently the board acted outside the law and the network is being sued by these two ex-employees. Written contracts could have avoided these two law suits, but what amazes me most is that settlements could have been negotiated before the disputes were taken to court, or even before the parties involved lawyers. These law suits will probably cost the network a lot of money which will have to be taken from grant monies. These are already being eroded by inflation and stretched beyond the limit by the expansion of the Network.

There's some kind of lesson in all this about keeping your house in order. Political activists tend to be far more interested in keeping the rest of the world in order than their own back yard. Organisational structures and systems are viewed with some suspicion because they resemble the world that needs to be changed. But I got the feeling that no one in the Network is actually looking after the network. There was no co-ordinator with an overview or to support other workers. No one seemed to care in an active way about how the board members relate to each other and how to foster an environment for sound and supportive decision making. Because the Network isn't being looked after, a lot of trust has been lost.

DECISION MAKING

Self-help alternatives by definition must have participatory decision making processes, but these are often compromised by the inadvertent mimicking of mainstream practices and by growing organisations which feel the need for more efficiency and formalised structures. I came across several decision making processes in the self help groups I visited and made some interesting discoveries about the decision making in my own organisation, Psychiatric Survivors.

DIRECT DEMOCRACY

Jenny (USA)

Jenny from the New England drop-in center was clearly committed to 'direct democracy'. But some of the members were ambivalent about participating in decision making.

It is sometimes very painful at our drop-in centre because we all have to make hard decisions at meetings; for instance, if somebody has been a persistent rule violator we have to deal with them. In a lot of ways it's easier to be inside an authoritarian structure because somebody else makes those hard decisions.

On the other hand there are negative consequences to being in an authoritarian set-up. There's a staff run club a few blocks away from us; we have a lot of members in common. The survivors don't like the fact that there's a staff phone and a staff room at this other place but they do like the fact that when there's a problem the staff deal with it. But on the other hand they do like the feeling of being in control and not being told what to do all the time.

MAJORITY RULE

Ed (Netherlands)

Clientenbond in the Netherlands started off with consensus decision making but there was too much difference of opinion to make decisions everyone was happy with. Ed explained the changeover to majority decision making.

I think we have lost the collective decision making that the organisation started out with. The one the most important principle we had in the beginning was that every single person had an equal voice. Some of our meetings would last all day to cover only four topics because every single person had the opportunity to speak on any issue. If one person objected, we didn't make a decision; the whole decision had to be rethought to include that person's objectives. Now we have more organised decision making where maybe one or two people or even more may object, but if the majority of people are moving in one direction then it's a matter of trust.

INVERTED HIERARCHY

Henry (USA)

Henry from a drop-in center in California had helped to create a membership led participatory decision making process.

Our decision making process is fairly complex. We are a membership organisation. The membership is entirely made up of clients. They elect the board which according to our bylaws has to be 60% mental health clients. We don't have any mental health professionals on our staff or on our board. All staff members except one are clients, so we are client-run from the top down to the bottom. The membership is on top; they elect and supervise the board who are mostly clients. The board supervises and hires the staff who are mostly clients. The trains don't always run on time but we have a good process that includes everybody.

HIERARCHY

John (USA)

John told me how his organisation had become more hierarchical as it grew.

We, unlike a lot of projects, recognised that we needed some hierarchical structure if we were going to grow and accomplish things. It is pretty much a traditional hierarchical approach here. The project directors take responsibility for a project and people report to them. We had to have a chain of command because we were growing so rapidly. Initially when our organisation was small, it wasn't that way. We all sat around the table and made decisions. There is still a lot to getting round the table when it comes to hard core decisions and issues that affect all of us. But we don't sit around the table and decide which computer system we are going to buy. We have a computer expert who is in charge of that.

Jenny (USA)

Hierarchies are so pervasive in our world that self-help alternatives are lucky to completely do away with them. Jenny a proponent of direct democracy wrote to me a few weeks after I had spoken with her in the United States.

Right now our members have become very dissatisfied with our group process. It makes me sad. They are looking for a more authoritarian structure, since a few people with difficult behaviours are making it hard for everyone else. One thing is clear; it's hard to develop egalitarian and participatory structures in an essentially hierarchical world.

FORMAL AND INFORMAL DECISION MAKING

I had a long talk to Ed and Wouter of the Clientenbond. Their organisation had established a formal decision making process to maintain democracy. Strangely, in Psychiatric Survivors we had associated formal decision making processes with loss of democracy. Suddenly I was made aware of the dangers of our approach.

Journal – On decision-making

Ed and Wouter explained that the organisational structure of their organisation gave equal power to all members. The final decision making body is the general meeting which takes place twice a year. In between, the board meets once a month. In between the board meetings a 'daily board' coordinating group meets weekly. The general meeting delegates to the board which delegates to the daily board. Everywhere I have gone on this trip, people have placed much more reliance on and respect for formal structures than we do in Aotearoa, especially to ensure that democracy is done properly. I can see more clearly now that formal power structures are necessary in case the informal power dynamics start to deteriorate.

Ed and Wouter asked me about the Psychiatric Survivors decision making structure. They were appalled to find that we have poorly attended general meetings and no equivalent to their board of directors. The workers run the organisation. At this stage I don't have any real worries about decision making in Psychiatric Survivors because the coordinating group has open channels with the rest of the membership. I'm concerned though that if these channels closed up the coordinating group could become a tyranny - accountable to members only once a year at the under attended general meeting. Although ordinary members can call special meetings this is not ensured in the way a routine board meeting is. On the other hand I'm against structures that strangle the initiative and innovation of its workers.

This constitutional warp has come about because two fairly distinct groups of members have developed in Psychiatric Survivors - the workers and the rest. Psychiatric Survivors has had paid and semi-paid workers since the day it began. In our first year or two, most of our active members became workers. I was adamant that everyone who gave their time should get payment for it. Unfortunately the rest of the growing membership got the implicit message that only the workers could have an active role in the organisation. In the meantime the workers gained knowledge, skills and status which tended to leave the other members behind, many of whom are multiply disempowered. Now the workers have enormous power and persuasion which is not being formally checked by the existence of a higher authority, representing the overall membership.

Currently the workers hold a weekly coordinating meeting. Some attempts have been made to get non-workers onto the coordinating group but without lasting success. I think a board should be established, with a mix of worker and non-worker representatives, to set policies and finance directions for the coordinating group to implement.

There's another trap though in thinking that just because you have the formal structure in place nothing else needs to be done to create a truly democratic organisation. An organisation that makes newcomers feel welcome, accommodates different viewpoints, treats members with respect and recognises their needs and abilities will go further than one that relies on formal structure alone.

LEADERSHIP

Pythia (Netherlands)

It is very important as chairperson that I create an atmosphere in which people trust each other. I need to hear all the people. I cannot speak for them all. I must not silence anyone. Every person has the chance to say something.

Leadership is a thorny issue in self-help alternatives especially the ones that are run by consensus or direct democracy. To many of us leadership implies power and power implies oppression. This journal extract wrestles with these implications.

Journal – On leadership

On my travels I've seen different leadership styles. Leadership style itself and other group dynamics are to some extent shaped by the vision of the group. In the United States there is a continuum of visions that go from those who wish to abolish the system to those who want to reform it. The abolitionist groups tend to have more flattened hierarchies and less obvious leaders than the reformist groups, which tend to be more hierarchical and have single powerful leaders. I may be over generalising, but it seems that the reformists who are not so thoroughly critical of the mental health system mimic its power structure more than the abolitionists do.

The reformists too, are less inclined to see the consumer movement in the general context of people's struggle against oppression; they do not see themselves so much as one piece of a general liberation struggle. The abolitionist groups though, which make up the original movement in the United States were swept into life by the liberation wave of the '60's and '70's. The reformists, I suspect were enabled to exist because of the liberalised attitudes of mental health workers in the '80's who promoted the more narrow vision of consumer participation in the services.

I have mixed feelings about both extremes of leadership styles in the United States. One of the more conservative reformist leaders has a lot of mana and people tend to 'look up' to him. I feel uncomfortable with this because it can mean that people don't recognise or use their own potential. On the other hand he has a strong vision and has lead his organisation way beyond the point it would have gone to without him.

The more radical organisations I visited talked a lot about participatory decision making but I don't think they practised it as much as they preached it. Their style of leadership could be more covert and subtly manipulative than the other style. At one place, the coordinator came across as very clear on power issues and consciously decided not to facilitate meetings with drop-in clients. But during the meeting we were at she interrupted the facilitator several times saying "no, you can't do that" or "it wouldn't work" and other similar things. Her power in that situation was very obvious to an onlooker.

As far as I can tell there are no powerful leaders in Britain. Perhaps the British are less inclined to cultivate super-leaders than the Americans. Some of the things I've noticed about the British user movement could inhibit effective leadership, especially the British tendency to form mixed survivor/professional

organisations which could discourage survivor members from taking leadership roles.

As a leader I continue to struggle with defining this role. I feel like I'm balancing on a very narrow plank between my powerful, single-minded, visionary nature on one side and my more timid, fair and politically correct nature on the other. In this work I've discovered I have far more leadership potential that I ever realised. At the same time I have cultivated the attitude that goes something like this: "As a survivor I have been subjected to hierarchical power structures and loss of choice which have damaged me. Any alternative I create or join must be participatory and non-hierarchical; otherwise I am as bad as my oppressors".

But another voice in me also wants to be heard. It tells me: "I have a clear, well thought out vision that I will not compromise. I have the power to persuade others that my vision is the one to pursue and the clarity to know what attitudes and actions are on track and what aren't. If this vision was under threat within the group I would fight for it like it is my own blood." This voice isn't all that concerned with participatory decision making but it has a wealth of clarity and energy. I need both voices to be in my leadership role but they do create internal conflict, especially guilt, particularly when I have done things that could be perceived as oppressive but which at the time seemed the only way to get back on track towards the vision.

I'm not sure where all this leaves me on the issue of leadership. I know it's important that some individuals with integrity and an agreeable vision take on this role. I don't think leaders should have any more decision making powers than the group is prepared to give them. Leaders should create an atmosphere where people can disagree and bring up alternatives. Leaders need to be clear about the group's vision and bring the group back to it. Leaders need to admit to themselves how much power they have (especially 'politically correct' ones like me) so they have the choice to use it overtly rather that covertly. Leaders need support and guidance from inside and outside the group. Leaders need to trust themselves and the group's ability to define their leadership role. Leaders need to know and use their strength and vulnerability to make them more effective leaders. The combined experiences of our own power and powerlessness should be used to keep us on the plank between dictatorship and wimphood. The final and overriding test of a good leader is how well their leadership unleashes the potential in the members of the group.

Since I wrote this several months ago I have begun to understand that there is clear and simple distinction between authority and influence; authority can be imposed whereas influence must be earned. I'm convinced that power by influence is the only way to run a self-help alternative, and the rest of the world as well. Unfortunately some client-run services I saw did not meet this expectation and had opted for traditional decision making processes.

MEMBERSHIP: ALLIES OR NO ALLIES?

There are two types of survivor groups; some admit just survivors and others admit 'allies' as well. Groups with non-survivor members are more common in Europe than in the United States. I have strong feelings about this issue.

Journal – On membership criteria

Because the British are more concerned with reforming the system they have a lot more contact with professionals. It is common for groups of survivors to admit professionals to their membership as 'allies'. In some groups the professionals have taken over; in other groups the survivors say they are happy with the professionals' involvement.

I am against admitting any other people to survivor groups. If any coalition with other groups takes place, a clearly identified survivor group should be involved. Individual survivors, without the backing of their own group are likely to be swallowed up by the others. Even in a coalition where several individual consumers are involved, their contribution is likely to be weaker because they lack a solid group identity outside that coalition.

Last night I went to the monthly meeting of a London borough mental health group. This is a mixed group of mainly users and some others. I think all the office holders have to be users and they can eject people from the group; this is particularly aimed at professionals who try to dominate. I think it's more likely though that any dominating professionals would drive the users from the group by making it a disempowering and pointless place to be.

The meeting started without any sharing or introducing each other. So I sat there the whole time wondering who was who and if they knew who I was. It was a dry boring meeting and I started dropping off to sleep. All the forum members are unpaid for their involvement. They meet only once a month. Combine this with the fact that they are mixed group with no mutual support

component and you don't have a very cohesive or strong group. However they do get quite a lot done; information pamphlets and other written work as well as representation on various mental health committees.

Because no introductions were made I was in the interesting position of having to guess who were users and who were professionals. In most cases it was easy to tell through dress, confidence, 'meeting skills' and language. The middle class users were harder to distinguish from the professionals, who are of course mostly middle class themselves. A lot of people did very little talking in the meeting.

A Chinese user was present and a Black user came in late, sat slightly outside the circle, said nothing and left. No attempt was made to recognise his presence. A retired psychiatrist also arrived late; this was his first meeting, yet there were no introductions. A couple of the users knew him and called him Doctor so-and-so. He spoke very authoritatively and peering over his half-glasses pronounced that progress and paternalism can mean the same thing. The chairperson politely disagreed.

I've got nothing against alliances of users and professionals who want to get political. I think there are real problems when the alliance group is the users' primary group. Ideally I would like to see these alliances draw on users who are already a part of their own user only group, where they get support, solidarity and clarity. This would mean that users go into these alliances with a clearer identity and more clout that the string of individuals users who go to this borough's mental health group who have no forum they can call their own.

Fiona (England)

Fiona from the south of England was positive about the role of professionals in the national survivor network though I doubt if they needed to be members to offer the benefits Fiona said they offered. The professionals could just as easily be advisors, called upon by the survivors when they chose.

The allies are mainly mental health workers and they are very conscious of the fact that they were not survivors. The whole point in their involvement was to enable survivors to take over. They offer the organisation a lot; they are experienced, most of them are actually unhappy with the system as it stands. Fortunately we haven't got psychiatrists practising the medical model joining Survivors Speak Out.

ETHNIC MINORITIES

Most of the survivor organisations I visited were predominantly white. This is a concern, as ethnic minorities and indigenous people tend to be over-represented in the mental health system. In my own country the indigenous Maori people have been experiencing a revival of their culture in the last decade or two. Maori survivors say that the loss of their cultural roots is largely responsible for pushing them into the mental health system. So their involvement in the survivor movement also needs to take them closer to their roots.

Hilary (London)

Many survivors I talked recognised that ethnic minorities aren't prominent enough in the movement but they didn't quite know what to do about it. I have also shared their dilemma.

We have had various discussions within the working party in our survivor forum about whether it is realistic to expect black and ethnic minority users to get involved with the forum or whether it is more realistic to try and facilitate them to set up their own groups. We are trying desperately at the moment to get funding to translate the booklet into the main ethnic minority languages spoken in the borough.

PAID WORKERS

Suzy (USA)

In the early days of the movement it was felt you shouldn't get paid for doing social action. You should do it because you are committed to it, not for the money. And you shouldn't take money from the mental health system because they would control you, and in a lot of ways this does happen.

Now there is a growing expectation that survivors should be paid for the work they do. A lot of the survivors I met in the United States are paid for their work but volunteers are still the mainstay in Britain and the Netherlands. I talked to Lisa in London about her experience with volunteer labour. In this journal entry I also reflect on the situation in the Netherlands and New Zealand.

Journal – On payment for work

Lisa has been involved in a few survivor only initiatives; mainly action groups which have folded. I asked her what went wrong in these groups. She said people's involvement was all voluntary and they didn't have enough time to put into the groups. Members lacked confidence and organising experience. Some came along for support rather that political action which meant business didn't get done because people wanted to talk about their problems.

Lisa's comments made me think back to the early days of Psychiatric Survivors. At the beginning I had an instinct to get funding to pay me a full time wage. Being a waged worker presented some problems because the unwaged members expected me to do most of the work and to have most of the competence. This brought me closer to the role of a professional than I was comfortable with. But having a waged worker from the start had some enormous benefits. It meant the work was far more likely to get done. It gave the group some status. I became a very positive role model which gave some survivors the confidence to seek paid work themselves. Being paid also encouraged non-survivors to take our fledgling movement seriously and support it.

Looking back, I think the advantages of having a paid worker from the start far outweighed the disadvantages, especially as I was so acutely aware of these disadvantages at the time. A paid worker has much more time and resources to develop themselves as organisers and leaders than someone who is unemployed or rushes to an evening meeting after a busy day of unrelated work.

In Psychiatric Survivors there is a clear distinction between paid and semi-paid workers who do virtually everything and the rest of the membership who do virtually nothing. In the Clientenbond though, the degrees of involvement are more evenly spread through the continuum of involvement, from being a full-time paid worker, to being a part time voluntary worker, to attending one meeting a week, or going to the drop-in occasionally, or to scanning the bimonthly newsletter on the toilet. I think that encouraging many degrees of involvement, as the Clientenbond does, is a real strength and needs to be done more in Psychiatric Survivors.

The existence of workers makes it more difficult for other survivors to be actively involved in their spare time and creates a gap that people using the support network may find too wide to straddle. The paid workers are very busy and go off to meetings to make decisions, while the people who sit in the drop-in

may feel excluded. The existence of workers implies they have expertise and responsibilities that are beyond the rest of the membership. They can form a class of their own.

FUNDING

In the United States funding for self-help alternatives is getting easier to find. In the early years of the movement there, funding was frowned upon particularly if it came from the mental health system. Things have changed. Someone told me that more Federal funding became available under the illiberal Reagan administration because self-help was seen to reduce dependency on the state.

In Britain funding for self-help alternatives has been harder to find under Thatcher's rule. The Netherlands has a relatively generous welfare system but self-help alternatives have not flourished there as they have in some parts of the United States.

John (USA)

In the real world people give you money to accomplish certain goals; they don't give you money and say 'go and have fun with it' or 'here is some money, sit around the table and come up with some good ideas'. You create the ideas and then you go and get the money, and once you have gotten the money you are obligated to do what you said you were going to do; you make a contract with whoever is funding you. Once you have made that contract you lose a lot of flexibility. I think that is something a lot of consumers have a struggle with. If you get any funding, you are not playing any more, you are doing business. I see a lot of consumer groups I consult with, who want to continue to play and to sit around and debate and have arguments. That's a lot of fun. I love sitting round debating and arguing, but once you get money you have to get the job done.

The group should really determine the contract but at a certain point the contract should be written down and then the group should be held accountable, and should not have any flexibility. If you say you are going to organise ten groups in a region, basically that is the contract. If, halfway through the contract, you decide you would rather have a beach house than a conference centre, I would say 'you guys are jerking me around' and pull your contract. If we are serious in the movement that we want user control and to take power, we have to learn how to do that. The challenge is how to take power and not become just like any other service.

Last word

The overall management of self-help organisations does not always reflect a self-help philosophy. If you want to maintain a truly self-help organisation it helps if you are small, radical, unfunded and don't offer a direct service. But the main dynamic behind our failure to manage our organisations along self-help lines is co-optation – when survivors unwittingly mimic the mental health system and other oppressive structures.

STOPOVER 8
CO-OPTATION

*When do self-help alternatives start to mimic
Conventional mental health services?*

Suzy (USA)

Our co-optation is not the kind that I thought it would be; we are not becoming diagnostically based, but we are becoming bureaucratically based. I think when you get big you probably have to have more bureaucratic structures, but I would like to see us create different kinds of structures that fit our uniqueness, which reach across instead of up and down.

KNOWING THE DIFFERENCE

The biggest lesson of my whole trip was that self-help alternatives can easily lapse into conventional services. The comparisons I made between self-help alternatives and conventional services in the last section are really idealised points at each end of the spectrum. In fact, I was disturbed to find that many of the self-help alternatives I saw were not all that alternative. Before I go on to discuss some of the less alternative self-help projects I saw I want to share two conversations as well as a few other insights survivors gave me on this problem.

FACILITATION OR SERVICE?

Ed and Wouter and I talked late one afternoon in Utrecht about the difficulty of the concept of a 'self-help service'. Is this a contradiction in terms? Can it ever be achieved? Should the principle of facilitation be used in favour of service?

Ed (Netherlands)

We started a runaway home in Amsterdam ten years ago and we were very optimistic of giving support by getting people to acknowledge the political aspects of their problem. Looking back I think it turned out to be a new way of

oppressing people. After three years I found out that we had obligated people to be very outspoken against psychiatry and we were creating the same dependent people that psychiatry did itself. It was very disappointing.

Because survivors have been in a position where we were oppressed and had no control, when we set up a self-help alternative we fear that we will do the same to other survivors as the mental health system did to us.
If true self-help is about people being independent or mutually dependent, maybe we should not provide direct services to survivors but facilitate and enskill people. They would be their own advocates or run their own support group or home, rather than having someone there 40 hours a week to do it all for them.

In New Zealand we did advocacy for people in hospital and the survivor who did it ran around with far too much work to do. People became very dependent on him. I saw we were just perpetuating the same old thing as Ed saw in the runaway house. If you are an advocate with an office and a big diary in your hand, survivors think you have special power to help; they are immediately disempowered and become dependent - even if you are a survivor.

But if instead, we had done workshops with a support group on assertiveness or ways to support each other or the Mental Health Act, we would just be facilitating a process where people could discover and use their own competence. Giving survivors skills and information, rather than just using yours on their behalf, means they can take more control over their lives.

When survivors start running a direct service like a runaway house, wider society and the clients who go there, see them as taking on some responsibility. They have to ensure that people behave within agreed limits and deal with breaches of those limits. If a resident goes crazy and they can't take any more of it they may feel like handing them over to the system. That's exactly the point at which the services start resorting to paternalism. Self-help services are no exception, especially those which have a weak identity as an alternative.

TRADITION OR INNOVATION?

Laura (USA)

I talked with Laura as she drove her truck through the town. This thoughtful young woman worked for the State network and had seen many self-help alternatives in action.

People aren't always bringing their hard line against the system into their self-help alternatives. I think some really traditional mental health programs are being developed by clients, and being passed off as alternatives when the only difference between that and a traditional program is that the staff are clients.

So how did Laura know when it is just a traditional mental health program and not a true alternative?

I can tell by the views of the staff members and the people who use the alternative service. I think people who are hooked into mental illness talk about medication and other traditional treatments are reflecting traditional values. Instead of relying on themselves for their direction they take direction from psychiatrists, case managers, family members. In false alternatives similar decisions are made to traditional mental health programs, for instance, about when somebody should go to a hospital or start taking medication. These kinds of decisions are starting to be made by self-help groups.

THE NEED TO SEPARATE FROM THE SYSTEM

Henry (USA)

I like biting the hand that feeds me and I won't stop complaining at the way the system treats people no matter how much money they give me.

Henry had no difficulty separating himself from the system. But for those who do have difficulty, their alternatives will never flourish while they identify with the mental health system, or allow themselves to be controlled by it.

Suzy (USA)

Suzy who was very clear about self-help lamented the direct involvement of the mental health system.

A lot of things are being called self-help that are not; they are really run by the mental health system. When this happens the self-help group doesn't run the program; they don't handle the money or make the major decisions. The mental health system does all that.

But the problem does not end there. Even self-help programmes with completely autonomous decision making powers run the more subtle risk of modelling themselves on the hierarchical structures they know so well.

I never thought five or six years ago that ex-patients would now be making real salaries. It is wonderful to see this whole self-help concept grow, but it is not always growing the way we hoped. In one client-run program the salaries differ from US $30,000 for the executive director to US $15,000 for a drop-in worker. It's the total hierarchy of a major corporation.

Lynette (USA)

Money from the mental health system may also discourage self-help groups from biting the hand that once hurt them but now feeds them.

The more recognised we become the more co-optation becomes a possibility. I think the easiest way to get co-opted is through money, and I think that happens all the time. It is a fear in any movement.

I frequently grappled with the issue of co-optation in my journal. I found that co-optation is particularly obvious in self-help organisations that are growing fast and are funded to provide a service. In my own rapidly growing and funded organisation, Psychiatric Survivors, we began to provide a service before we had time to ask: "Can self-help activities ever become services without compromising their self-help qualities?"

Journal – On co-optation

So far this trip has aroused my anxiety about survivors assuming the role of hands-on providers. Of all the consumer run services we have visited only one has appeared to be free of the destructive elements found in conventional services. Of course these consumer run services are preferable to conventional services but it still upsets me to see elements of conventional service provider behaviour creep into them. It's not surprising though that they do. As survivors we do not just have the oppressive mental health service model to absorb. We have absorbed authoritarian, hierarchical patterns all our lives; in the family,

the education system, as employees, as oppressed minorities. No wonder it is so difficult to shake off.

The risks that survivors take when they assume a helping role have not be explored enough by people in the movement. The question is, how do survivors ensure they provide a true alternative and don't end up like their oppressors? The usual answer from survivors goes something like this; "because we've been through the same experience, we know what it's like to be oppressed and we wouldn't make it happen to others". This type of reply totally ignores all the other experiences survivors have had which have made them into what they are today. Even if we don't have any power in society's authoritarian structures, these structures have taught us particular ways to relate to other people, unless we consciously decide not to relate that way. When survivors come into the movement they are carrying much more than just their survivor experience but a lot of other baggage which they can unwittingly use to oppress other survivors.

The unwitting oppression of survivors was most obvious to me in two places I visited; a support centre and a large survivor organisation, both in the United States. I have difficulty being so thoroughly critical at honest attempts at self-help by my friendly and hospitable peers. But I have learnt a lot from their mistakes as well as my own.

THE LINE BETWEEN SUPPORT AND COERCION

One of the first visits we made was to a support center in the United States. This center has a good reputation and a few days after I wrote the following journal entry I talked to the co-ordinator who has impeccable self-help credentials. He told me that the upstairs accommodation was not run by the support centre but he didn't quieten my other concerns.

Journal – On my visit to the support center

The door was open and a tall good looking black man called Victor appeared to be preaching to a dingy roomful of seated people, mostly blacks. He welcomed us warmly and asked us to take a seat. He introduced us as honoured guests from Australia until we corrected him. I felt a bit too honoured for my own comfort so I got up and said a few words about my psychiatric experience, the one thing I knew that equalised us. Apart from that I know we must have come across as very privileged and important to them.

While we were settling in, the immaculately dressed Victor continued to give his moral perspective on concerns raised by the clients. To one he explained that as people go through the program at the support centre they learn that making love in the back seats of cars is not the thing for them; they learn that making love in relationship is morally better. Soon after, a man began to walk out the door. Victor stopped him and said in a strict fatherly way "Go back inside or don't come back. We've made an agreement that you won't wander in and out." These dynamics are familiar enough to me but until today I assumed they would always be avoided in any organisation that calls itself "self-help" or "client-run" as this one does.

The support centre provides a drop-in and living skills programs for the homeless ex-mental patients in a poor urban area. Upstairs, on the first floor there is temporary accommodation for, I think, over 20 people. The floor above this is called the Penthouse where a few make it to relative luxury and spaciousness, on their way to completely independent accommodation. It's almost like the floors are arranged to make a metaphorical statement about going up in the world and about how people who are good in the eyes of the support center deserve more space and comfort than the others. They even have a view. Down below people are packed into dormitories which they are not allowed into during the day. "Why?" I asked. The supervisor said there wasn't enough staff to look after them. They were too busy doing their paper work; the plague of any community organisation catering for people with urgent needs.

The people who use the support centre do have urgent needs. As well as their homelessness and psychiatric backgrounds which are the two criteria for membership, many of them are drug addicts or alcoholics. I could tell there were a lot of very damaged people among them.

Victor and another man, an accommodation supervisor, showed us around upstairs. As they talked about the support center I noticed their pessimism about the clients, an attitude I have always assumed ate away at only the workers in mainstream mental health services. These two men, at least one of them an ex-client, shook their heads saying that hardly anyone makes it up to the Penthouse. This attitude disturbed me. The accommodation supervisor said that he had made it up to live in the Penthouse and that the support center liked to employ ex-clients. Victor wasn't so clear about his background. First he said he hadn't been a client then he said he had. Perhaps he picked up my curiosity about whether staff were ex-patients or not. I believe strongly that they should be.

Something in me continues to feel unhappy about the centre we visited today. Perhaps Victor's preachy style is okay with black people but I would have felt condescended to if he talked to me like that. I cringed when he pronounced his one true sexual morality to a roomful of grown adults and left no doubt that clients should not have more than one partner; otherwise they could not be making progress with the center's "relationships program". Victor is a nice warm guy and he did say to us "Talk to the clients; they're the real experts." But I was also unhappy about the way he pressured the man who was coming and going. Could the centre have a casual space and another space where people can get on with the program without interference? It seems quite overcrowded so perhaps this would be difficult.

My own philosophy about self-help alternatives pared down to one sentence is this. A true self-help alternative is one which recognises and encourages people's abilities and doesn't take too much notice of their disabilities. In the mental illness system it's the other way around which is what is so destructive about it. I came away from my brief glimpse of the support center today feeling that the clients' abilities could be given more room to grow.

SELF-HELP GETS LOST IN BUREACRACY

Soon after my visit to the support center I spent several days in a large survivor organisation in the United States.

Journal – On the organisation

The first thing I noticed about the organisation was its enormous size. It employs about 60 survivors who operate about 11 or 12 programs ranging from residential services, advocacy, job training, support groups, drop-ins, consumer case management, to technical support to survivors at state and national level. Its offices take up most of two floors in quite a large building. Many of the employees work away from the main office.

The workers here have made us feel really welcome. Several of us had lunch with their leader the other day. I found him to be a very likeable and direct person. As we talked I could tell things were a bit shaky with him. We found out later that he had put himself in hospital. His wife told me he wanted 'shock' which distresses her. He has always been anti-shock. Others wonder why he put himself into a hospital when he comes from such a self-help perspective.

I have problems with this one too. To me self-help and conventional mental illness services have to be slightly allergic to each other which means they can't mingle that easily. I'm sure the more deeply dependent a person is on conventional services the less open they are to the self-help approach. I wonder what effect a leader has on self-help organisation if they demonstrate a dependency on the services. Does it create a confusing, contradictory role model? What would have happened to the tone of Psychiatric Survivors if I had been heavily into the services? Apart from my absence would my use of the services subvert the self-help basis of the group?

I want to learn more about the dynamics of this organisation but so far my questions have not been answered in much detail and I'm too reserved to probe any further. I want to know more about the leadership and distribution of power within it. Does everyone have enough of a say? How autonomous are the different programs? How far would a program have to stray from the organisation's philosophy to be brought into line or ejected? Is there room for more than one leader? Is recognition fairly distributed? I can't seem to get satisfactory answers from people to these questions. Sometimes I feel that people are a little defensive about organisation. Also, they might not think a lot about these issues, which indicates to me that their decision making and group dynamics follow traditional patterns more than alternative ones.

I'm impressed with the size and diversity of this organisation. The workers are very dedicated but the office has a slightly bureaucratic feel about it. Political analysis has not been all that high on the agendas of the people we have talked to. These things may be the result of being in a large organisation which keeps its workers stretched to the limit. I have seen none of the clarity of vision or theoretical strength of the people I talked to in San Francisco. This organisation began only six years ago, whereas the survivor movement in California came out of the radical protest atmosphere of the late 1960's.

Another aspect of this organisation I don't understand well is its relationship with the Local Mental Health Association. According to one worker, the organisation is autonomous in relation to the MHA, though the leaders and the MHA director have regular meetings. The MHA is an umbrella organisation for the organisation. All the organisations funds are raised and administered through the MHA despite the fact that the organisation is incorporated itself. As far as I know the MHA doesn't make decisions about money but it does the wages for the organisation and I wonder if someone from MHA is a signatory to the accounts.

Psychiatric Survivors received its funding through a mental health promotion organisation for the first year, until we became incorporated. Though the organisation did not control us in any way, I was eager for Psychiatric Survivors to apply for funding in its own name and take full responsibility for our expenditure. I can't understand why the organisation would choose to remain in this relationship with the MHA.

I asked one of the workers what would happen if one of the programs deviated from the organisation's self-help philosophy. Who would have the final word? What if the organisation's leader didn't respond to a problem? His reply was that the director of the MHA would have the final say. This didn't seem to disturb him. This worker may be mistaken about this. I hope he is. But the fact that it entered his mind that the MHA director could take control is significant; it reflects an unclear vision of what self-help really is.

JOURNAL - VISIT TO A RESIDENTIAL PROJECT

Today we visited a residential home run by the same large survivor organisation for up to 18 ex-patients, most of whom have been homeless. It's a comfortable, well equipped place with three stereos, nice furniture and new paint and carpets. The manager showed us around. First we went into the kitchen. I spotted a notice by the door which said something like this: "Clients are not allowed in the kitchen unless accompanied by a staff member." This statement does not come from a self-help perspective. Even if there was a good reason for the clients not to use the kitchen, in a truly self-help environment the notice would not include the punitive expression "not allowed". Instead it would indicate a collective decision, not one that is being imposed by staff onto clients. Because the distinction between staff and clients is necessarily blurred in a true self-help alternative, everyone is expected to take more or less equal responsibility for what goes on, rather than the less responsible clients being "accompanied" to the kitchen by the more responsible staff. The notice could have read something like this: "The people in this household have agreed to use the kitchen as follows... You could even question the use of a notice at all; notices are an institutional form of communication not found in many ordinary households.

We left the kitchen and walked down the hallway. Next to the office I saw a door with a notice saying "Staff lavatory - keep out". If there is one single gesture that can immediately separate conventional services from self-help

initiatives, it is whether workers share the toilet with clients or not. Separate toilets indicate a perception that there is and ought to be a hierarchical and hygienic distance between worker and client.

In the office Jackie spotted another notice - "Barry is to be given one cigarette at a time because he was caught smoking in his room." This notice speaks for itself. Peers don't 'catch' each other doing 'bad' things. They don't put confidential notices inside a closed office with a prescription for a staff response to non-conforming behaviour. If they do it's because they have been so thoroughly soaked in the service model they don't know any other way of interacting.

The two upstairs floors hold the women's and men's bedrooms which had two to three beds per room. Each door was labelled with a number and each bed was labelled with a letter of the alphabet. The manager knocked on the doors. If someone answered she asked their permission to show us the room. If no one answered she showed us the room anyway. My heart sank when I saw the numbers and the letters - I felt like I was in a hospital again. And I felt really uncomfortable going into people's rooms without their permission.

I asked the manager what part the residents had in the household decision making. She said they have a weekly meeting with the residents to discuss things and all complaints were followed up. The residents also meet regularly with a 'peer advocate' away from the staff so they can discuss things openly without feeling intimidated by the staff. This comment interested me. When I first heard it, it sounded good. Then I thought back to the way we have organised feedback in Psychiatric Survivors. It has never occurred to me that the people who use Psychiatric Survivors might feel too intimidated to give feedback in front of the workers. I think this is because they don't feel intimidated. The manager's acknowledgement that the residents could feel intimidated in the presence of staff was an unintended indirect admission that she was running a conventional service and not a self-help program.

Well, I don't think much of this residence. But considering the abuse and homelessness many of the residents are taking refuge from, the place is a haven and light years ahead of homeless shelters. In this context my criticisms may seem like nit-picking. But the residence is part of a large survivor organisation and in some ways it is defying its consumer identity. After our visit, Brendan asked Jackie and I if we thought the manager was a consumer or not. We both said "no" straight away. The manager is not a consumer. What is she doing there then?

Last words

Co-optation or mimicking the conventional services is the most insidious and disturbing development in today's survivor movement and it needs to be faced up to. If self-help returns power and competence to survivors this must be reflected in our alternatives. How can we ensure that consumer run services don't degenerate to the level of the conventional services? The parameters of our behaviour in the self-help setting need to be much more clearly thought about and defined. Standards need to be spelt out and a system for encouraging these standards needs to be put into place. Of course these standards need to be totally created and maintained by survivors.

MY JOURNEY ENDS

THE WEAVING OF EXPERIENCE, IDEAOLOGY AND PRACTICE

I flew back into Auckland on a cool June morning. In the snatches of time between meetings or over morning tea people would ask me what I learnt. But a great flood of impressions and ideas would crowd my mind and I was unable to say much about it. I told people it would all be in my report but it's not quite finished yet; someone told me I need to tie the report up with a final chapter.

Looking back, this report is the working and reworking of two themes. The first theme can be condensed into the word 'meaning'. What is the meaning of our madness? How does that meaning contribute to the ideology of our movement? The second theme is 'management'. How do we manage our activities so they will truly reflect our ideology?

You see, I'm still asking these questions in the final pages. My journey didn't really answer them, but it did something even more important than that. It showed me that basic questions like these are not addressed enough. It's so easy in the busyness of life to forget the questions that drive our movement. During my trip, away from all the distractions at home, I had the 'space' to return to these questions.

The first question is what is the meaning of our madness? The first job of any movement is to redefine who we are and what our experiences mean to us so that we can live more comfortably and creatively in the world. Our redefined experience then needs to underpin our ideas on the way the survivors should be in the world and with each other. Then we need to ensure that our ideas about who we are and what we should be become integral to what we do.

When we fail to link our experience with our ideology and our ideology with our practice we are no longer a powerful force for change. Instead we tend to parody the system that has dehumanised us. Movements often have radical and ideologically strong beginnings but as they grow they tend to moderate and lose clarity. In our own growing and diversifying movement the basic questions seem to be more lost than ever. My only recommendation in this whole report is that we return to them.