

European Network of Users and Ex-Users in Mental Health

# Our Own Understanding of Ourselves

Report on the Kolding Seminar

16. – 18. December 1994

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**European Network of Users and ex-Users in Mental Health**

# Introduction

Can psychiatric survivors, ex-users and users/consumers be brought together and form an NGO (Non-Governmental Organisation) on a European level? A difficult question that cannot be answered only theoretically. To build an NGO you need members, who find that we share some common interests and common political and ideological viewpoints.

To start off the process leading up to proposals on ideology, politics and actions at the next and third Conference of the European Network of Users and ex-Users in Mental Health, the Board of the Network invited individuals with different experiences and opinions from the survivor/usermovement to meet and discuss some fundamental questions. 30 users/survivors from 11 countries participated.

While most of the time at our former conferences was spent on medical and legal issues, the focus for this seminar was on social issues.

The questions put to the participants were:

1. a. Self understanding: Are we different from average citizens? If so, why?
1. b. Self definition: How do we define ourselves without using traditional psychiatric or disability terms?
2. a. Self determination: How do we achieve self-determination in our own social surroundings?
2. b. Special rights or just equality? Should we demand special social rights (e.g. work, housing, money) ? If so, which rights would be our priorities?

These questions were discussed in smaller groups and were later on debated in plenary sessions.

This report sets the written comments from individuals on particular topics beside the reports of the plenary sessions. This gives the flavour of the ideas and shows the development of the interactive debate. The reports of the plenary sessions reflect the different styles of the rapporteurs rather than the length of the plenary-debates.

The clear understanding from the beginning that the seminar was not intended to reach any final decisions but to share ideas and opinions resulted in a very open and honest atmosphere. All participants took part in the lively discussions and everyone felt that his or her opinion was taken seriously.

Many different concepts and interesting angles were brought up. Most of the participants found that the questions were not that easy to answer and that easy answers might be dangerous to give. Among the concepts which kept coming up were:

- vulnerability - survival - sensitivity
- being: misunderstood - stigmatised - humiliated - discriminated against
- not coping - reluctant to adjust - experienced - natural

The Seminar showed a wide range of theoretical and ideological views amongst individuals in the Network as well as their capacity to listen and learn from each other.

The Seminar challenged the Board and task-forces to strengthen and clarify our descriptions, aims and objectives, and to use words, concepts and views, which will unify instead of split the user-/survivor movement.

Comments and suggestions on the questions and items of this report are very welcome at the European Desk of the Network.

# Gratitudes

On behalf of the European Network of Users and Ex-users in Mental Health we want to thank :

- The Commission of the European Union and
- The Danish Ministry of Social Affairs for their financial support
- DPI, The Disabled People's International London and
- SUS, Socialt Udviklingscenter Storkøbenhavn, Copenhagen for their support
- Users and Survivors for taking part in the seminar
- Jan Dirk van Abshoven, former secretary of the European Desk of the Network for all his preparatory work

The Board of the European Network

# Part one: Self understanding and self definition

## 1.1. Written contributions from participants

### 1.1.a. Self understanding:

*Are we different from average citizens? If so, why ?*

*Hans Bergström, RSMH Sweden.*

I don't like talking about normality and so called abnormality. We are just people. But for the man in the street we, who are Psychiatric users or Survivors, are different. Psychiatric illnesses are the last shameful diseases. Even AIDS has got a face amongst the public. There have been a lot of gala performances where famous actors appear to the public, but we haven't yet got a big gala performance for users in mental health. And how can the public look upon us as "normal" people? During centuries we have locked up people, suffering from a mental disease, in mental hospitals or asylums. People learned that we had to protect the society from the "madness".

And now the same public shall meet the same persons as neighbours, in the supermarket, and maybe at their works. There is a shift of paradigm that goes very rapidly.

*Jasna Russo, Boardmember, Yugoslavia.*

Our experience of psychiatry is what differentiates us from other people. I don't find it safe in a society as it is, to speculate about other eventual differences. Not all of us did go crazy before ending in psychiatry. And not all of us did make trouble. We might see ourselves as more sensitive than others, but I think we should gain any common self understanding. It's all right when each of us find the meaning to our own experiences, and there are as many of those experiences as there are of us.

*Eva Feiglová, Czech Association of Mental Health, Czech Republic.*

According to my experience from talks with fellow-patients and my own perception of the world and society, I think that we are more sensitive than the average population, more sensitive to our own difficulties in life but as well to what our fellow men feel. Often we are willing to help them. If we are joined in organisations or clubs, it gives us opportunity and ability to do so. Our hard life experience gave us the privilege to be able to listen to other people, to understand them and to know that we have no choice between the struggle for life and mental hospital, because the second is too horrible to be experienced again.

I heard a wonderful metaphor, depicting my feeling of how we differ from average citizens: Some people are like a canary in a coal mine, which was used in older times for the signalling of the poisoning gas in the atmosphere. The canary died first, just before the people under the earth started to be endangered. In the same way we react to the disharmonies and insufficiencies in the whole society. It means that on the other hand we can help other people, as we are sensitive enough to their feelings, needs and demands from the society.

*Kerstin Kempker, Berlin, Germany*

Are we different from average citizens? No. We have to make public, that "mental illness" is more an issue of belief than a scientific reality (but there are a lot of real reasons to get crazy) and therefore we don't

need diagnoses, psychopharmaca, shocks and compulsion, but all in society need more tolerance, less normality and less fear of abnormal behaviour.

People who need and want help, should get the help they wish. They should have the possibility to choose between real alternatives. Treatment with harmful effects (Neuroleptics, shocks), e.g. chromosome damages and tumour buildings in the breast glands resp. brain damage, has to be prohibited at the same time.

For me (and our union) the political and legal issues are of great importance. I'm not fighting for nice words and wishes, but for real changes, which have to be enforced. Psychiatrists will not make a voluntary surrender.

***Neil Ward, Survivors Speak-Out, United Kingdom***

Are we different from average citizens? Answered simply, I think yes. Those who have, are, or become labelled 'mentally ill', have done so for reasons that go beyond their particular behaviour at this or that point in time. I think we are fundamentally different in the way in which we 'view' the world. Perhaps most significantly to me, the way in which we feel the real world 'out-there' to be, often lies in marked contrast to the ways in which a society tells us the world really is. I think the mad become labelled so, due to our normal, rational and human inability to constitute our experiences in terms of the prevailing social order.

***Theresja Kruppenacher, Les Sans-Voix, Switzerland***

In a sense we are different because we know better than "the average citizen" what it means to suffer, to be humiliated, to be considered a "mad" person, an incompetent, irresponsible, social non-entity. True, we are often more fragile than "the average citizen" because of the circumstances we have had to live through and which have caused, or are linked with, our more precarious state of health: sickness, accidents, loss of kin, friends or professional status, difficult family surroundings such as incest, alcoholism, violence, etc. The stress we have undergone, together with the way we have been treated, tends to make us lose our self-confidence and sometimes even our self-esteem.

We think it is a good idea to focus our attention for once on social issues, i.e. social recognition, integration, rehabilitation. However, it is not possible to separate social issues entirely from medical ones, since our state of health determines our social needs. Nor can legal, economic or political issues be evacuated as they all interact in determining social rights and conditions.

However we are definitely like any "average citizen" in that we know better than any outsider what we feel, what we need, what is good for us. We have had ample opportunity to reflect about what is happening to us, to try to understand ourselves and others and in a way we are experts in self-understanding. What is certain is that no one understands us better than ourselves.

***Mary Nettle, MINDLink, United Kingdom***

Yes we are different from average citizens because of the discrimination we face from being labelled mentally ill. Inside we are no different from the average 'normal' citizen who could easily given a combination of events such as the sudden death of a loved one, being made redundant, from a job or becoming homeless join the ranks of those labelled mentally ill. It is only our contact with the psychiatric system that makes us different.

*Maths Jespersen, RSMH, Sweden*

On the one hand we are just individual, human beings like everybody else. On the other hand we cannot and should not deny that we have had special emotional, psychical and spiritual experiences. This might seem as a paradox and a contradiction, but for me it is not. The solution of this paradox is that we might have had very special and rare experiences, but these are in the scope of normal human reactions. They are no illnesses or deviant behaviour or disorders or something like that. They are some of the reactions that human beings can manifest under some special conditions.

We are individual human beings, but we have some typical kinds of reactions in common - like anger, fright, falling in love, blushing and the different emotional, psychical and spiritual experiences indicated above. The typical kinds of reactions are common, but the situations in which they arise are very personal and different. And these situations are in their turn part of very different contexts, emerging out of our personal history, which is unique.

As these reactions are normal though rare they shouldn't be the subject of treatment. They aren't something you should be cured or rehabilitated from. They are experiences that should be lived, that should be seen as meaningful events in your life story with important messages to you about how to live more authentically and worthwhile. These experiences might bring about much suffering to you, but they are not to be neglected or to be denied or to be pressed down with drugs - one needs to find the way through.

I also think that we have some common traits, which might be part of the reason why these special emotional, psychical and spiritual experiences happens to just some human beings and not to everyone. One common trait I think I have found in most of us is that we are very reluctant to adjust to the behaviour and thoughts of the majority. We are the real individuals, who don't want to submit ourselves to the conventions and norms of "ordinary people".

We don't want to be part of any collective- and that is also why it is so hard for us to find some new common name of our European Network and to find a common categorical concept to replace "mental illness".

But I think we must find some new common concepts and ways to describe our special emotional, psychical and spiritual experiences. We cannot just say "No" to everything, we must have some positive alternatives.

If we just deny that we have had these special experiences and don't want to talk about them, we are false to ourselves and to the deep, meaningful messages hidden in these experiences. We are then just damaging ourselves and multiplying our suffering. We are then also in exactly the same position as psychiatry, as denying our experiences is just what they are doing - with the help of drugs.

We must turn our suffering and hard experiences into something positive and therefore also define these experiences in a new and positive way. They shouldn't be seen as something negative but as something wonderful with a profound relevance to ourselves and mankind.

Just as the blacks in America turned their black stigma into something positive by saying "Black is beautiful", we might perhaps do the same by declaiming "Mad is beautiful" and start being proud of our experiences.

Our experiences are not "mental illnesses" or "disorders". They are natural, adequate reactions in the existing scope of human ways of manifestation.

They are in no way confined to "mental patients". They are well known throughout all mankind's history. Our special experiences are common with those of many shamans, mystics, artists, profound and moral

personalities among the poor people and all kinds of men and women who break out from their devastating social confinement to find a way of their own to a more authentic and worthwhile life.

These links are well-known, hard facts. When psychiatry is denying these facts by trying to press our experiences into the concept "mental illness" they are simply lying.

Conclusion: We have to define and describe our special emotional, psychical and spiritual experiences in a new, positive, creative way.

***Stefania Dei, A.I.S.ME, Italy.***

There isn't any way which distinguishes us from the other average citizens, in my modest opinion. Everything depends on the people with whom we are in touch every day, if they are not clever. Therefore there are some people, this does not depend on their cultural level, but it derives from their clever standard, who want to take advantage of the person labelled as someone different or because they have a weak personality. On the other hand there are some people who are clever who don't perceive us as different people, or better still give us all their friendship and love because they do not want us to feel even more our inferiority complex because emotionally disturbed people are highly sensitive.

***Giampiero Fossi, Gruppo d'Auto-Aiuto Psichiatrico di Firenze, Italy***

Each user or ex-user is a citizen like all other people. Each person-citizen has his/her rights and duties. A user or ex-user, otherwise needs structures for social re-insertion; actually they are few in my country. In Italy we have several social co-operative societies (so-called "social private"), that put into effect working reintegration programs for ex-users, whether inside the co-operatives or out of the co-operatives, in some small local industries, in cleaning enterprises etc.

Most of the people that live in a family (seeing that the pensions are very low) have a lot of difficulties to find a job autonomously, especially without a "right acquaintance".

We also have the "stigma", the "mark" ( that springs out of medical diagnosis), it makes worse working and social reintegration in "normal life".

I think we can recuperate a person through:

- a) work/job
- b) activities for spare time
- c) affective life

***Lars Jensen, Denmark***

Apparently we must have been different from people surrounding us, since they succeeded in pointing us out for psychiatric treatment that caused and created stigma and handicaps, which fulfilled all bad expectations and which was totally disabling, invalidating. But why?

Higher sensitivity and/or more stringent and consequent in thinking and prophecy undermined existing power and prestige relations in our surroundings (in politics, in family, and job).

So, all the bothered and annoyed people defined us cantankerous and the psychiatric constructed "our" exact diagnosis to explain "scientifically" all divergences and quarrels.

***Marinka Kapelj, SENT, Slovenia***

We are not different from average citizens, but the "normal" part of our society think that we are, because they are afraid of their own madness.



### **1.1.b. Self definition:**

*How do we define ourselves without using traditional psychiatric or disability terms?*

***Hans Bergström, RSMH Sweden***

This is a very difficult question to answer. But for me it's a question of vulnerability. But it's also a question of disability. When we in Sweden talk about disability it's a question of relation between the individual and the society. That means that you lead your thoughts away from the individual towards certain lacks in the environment that can be dealt with. With that I want to say that the democratic society has a responsibility to make it possible for each individual to take part in spite of your own disabilities or malfunctions.

***Jasna Russo, Boardmember, Yugoslavia***

The same as self understanding. We are not handicapped, neither disabled or ill. What is there about us that needs a definition? Do the people who haven't been diagnosed need to explain or define themselves? Shall we accept the reasons for psychiatry and help them define the difference? Help them draw the line once more? I can individually keep defining myself in a positive way (for example as someone who can get totally sick of this world and allow herself not to be a part of it for a while) and I can discuss it with friends or write about it. But I find it very dangerous and I am against us together tending to find common categories for all of us. Our survival of psychiatry is what brings us together. And our self definition should end there.

***Eva Feiglová, Czech Association of Mental Health, Czech Republic.***

The problem of what is normal and sane - if the norms of the entire society which lead to the consumer's way of life, loss of values, stress on competition instead of co-operation, violence, etc. - or reaction of more sensitive individuals who do not fit into the society, is well known and it is difficult to make people think about it.

In mental hospital I met also people after death of the nearest person or divorce of parents - a situation quite understandable as a cause of breakdown. The society should provide services in the range of the "norm" helping people to cope with crises.

***Kerstin Kempker, Berlin, Germany***

We are "survivors of psychiatry" (common experience) I prefer: "antipsychiatric activists" (common aim) "(ex-)inmates of psychiatry" is a more neutral term but all these words are only possible names for a union. They don't define me or others as persons. I don't want to be defined once more.

***Neil Ward, Survivors Speak-Out, United Kingdom***

How do we define ourselves without using traditional psychiatric or disability terms? I think a good start would be 'misunderstood' and 'ill-conceived'. Perhaps from this social perspective, we might usefully define ourselves individually as people and collectively as, possibly, THE EUROPEAN NETWORK OF PEOPLE DISPUTING PSYCHIATRIC PRACTICE.

***Theresja Krummenacher, Les Sans-Voix, Switzerland***

We are people whom other people have labelled, diagnosed, stigmatised as being "mentally ill". We are people whom other people treat like "objects" and not "subjects".

Like other human rights minorities we refuse this stigma and especially we refuse to be second-rate citizens. We are human beings with emotions, feelings, desires, and especially rights and responsibilities.

However, we must recognise that, submitted - sometimes forcefully - to the authority of others, we have often become handicapped, multi-dependent, both physically and financially and perhaps psychologically. We need to regain self-confidence, self-esteem, and especially self-determination.

***Mary Nettle, MINDLink, United Kingdom***

If only we could define ourselves without using the labels that psychiatry and society puts around our necks. I like the name survivor and I accept the use of the label service user. I personally do not feel it is associated with drug user although many people do (anyway a lot of us are users of prescribed drugs). We are all human beings who sometimes have difficulty in coping, quite often interference from psychiatry makes us less able to cope. I would like to be defined as a person whose needs are no different to any other human being.

***Stefania Dei, A.I.S.ME, Italy.***

How do we define ourselves without using traditional psychiatric or disability terms.

We are a particular kind of people who are leading our lives with certain feelings of being ill at ease. It is possible to see the reason for this in Modern Society where the number one person always seems to be one of the most materialistic, having one of the sharpest minds and being one of the best known people in society. First, I have to say to myself, then I would like to cry out to all the people who experience the same troubles as myself that we would have to be optimists to think we could succeed in doing things in exactly the same way as those other people are doing.

The most important thing is to know ourselves thoroughly so it is possible for us to understand what our real intellectual capabilities are so we can prepare ourselves for a job in the future.

***Giampiero Fossi, Gruppo d'Auto-Aiuto Psichiatrico di Firenze, Italy***

We define persons like others, without psychological-medical marks.

In case of need we want to have the right to ask for help without being discriminated.

We want to have the possibility to work, to love, to amuse ourselves as all people do.

Theoretically, it's possible to do that, but the practical realisation is really difficult.

***Lars Jensen, Denmark***

I am I. You may ask me questions to find out, to reveal or to judge, who or what you think I am.

***Marinka Kapelj, SENT, Slovenia***

We are survivors or users of psychiatry. We use both these terms in our organisation. But we do not want that other people use these terms for us. We don't want to be defined.

*Peter Campbell, Survivors Speak Out, UK (not participating in the seminar)*

I feel personally that the question of how we are saying we are different is very important. Not only the difference between "survivors" and "non-survivors" but between us and other disabled people and the differences between "survivors". For example - is there a significant difference between people with "psychotic" and "neurotic" experiences? I feel there are differences in the last case and not just in terms of experience in system of care e.g. whether we get ECT or talking treatments.

Also feel issue of self-definition is important and whether we would share the concept of "disability movement".

I hope Kolding is successful.

## **1.2. Plenary session**

### **Abnormal or experienced?**

Maths Jespersen gave a summary of the 3-hour long discussion of his group on Self-definition and Self-understanding:

The group had agreed from the outset on the question of 'Are We Different?' to separate being persons who were the same but individually different as is every citizen from the acceptance that we have had non-ordinary experiences.

It is the bio-medical model which makes the experience into a label/diagnosis by the psychiatric system. We recognise communality but there is a need to separate our personal history and social context, even the trans-generational picture. What is this concept of 'Mental Illness'? The group saw it as something of spiritual crisis, but this can be problematic because of religious overtones, so possibly it has more to do with emotional crises and distress. While we need to look with a critical eye at things, it is important we describe our experiences carefully with the positive aspects included. If you see this as a medical illness you lose the part played by personal history, meaningful experiences and outside influences.

Are there common threads in our lifestyle? We do not want to be average or to adjust to society. Eva had said 'We do not want to live in the world just as it is!' Normality, what is it?

Roberta: What we share is not clinical but emotional - do we have a wider range of emotion than most people? We do not want to be average or to adjust to society.

Jan Dirk: Is that really the case or are we just unlucky? Is it an arbitrary matter of chance? 'to live in the world just as it is!' Normality, what is it?

Maths: You must make a difference between being a human being and having special experiences. As human beings and citizens we are like everybody else, but we have had some special extra-ordinary experiences, which not all people have. But these experiences aren't limited to people labelled as mentally ill. There are also people who have survived outside of psychiatry with these experiences and in some other cultures these experiences could be recognised as something meaningful.

Roberta: Are there states everyone experiences but sometimes categorises as something different.

Eva did not agree with society, did not want to adjust to the world which permitted the holocaust of the six million Jews in World War 2 and now the 'ethnic cleansing' and wholesale slaughter in what was once Yugoslavia. Eva's daughter was always being told she must adjust too. As people Eva believed we are thinking more about others, we are helping each other, not competitive. In the wider world there were other values- efficiency, competition. We can explore the world in very sensitive ways because we are very

sensitive. We can sometimes be efficient. Sometimes we want to be efficient but we use up our energy and abilities and have need of support.

Hans: To abandon and reject society is to reject yourself as you are a member of the society.

Eva felt that to abandon society is to abandon one's self in-society. Even if living in society that seems mainly urban and Western means that it values efficiency and the material rather than relations between people.

Erik O. reminded the seminar that in nazi times not only Jews but also people who used psychiatric services were killed off. He believed that there is a danger that if we define ourselves too strictly as different from others it could one day make it easier to separate us out and to kill us.

Erik K. believed it was not possible to give definitions of normality. He said that his wife said that he should be different in her way, doctors in the hospital said he should be different in their way but he only wanted to be different in his own way.

Matthias: We must recognise what in German language is called 'Definitionsmacht'. We can define psychiatrists as criminals.

Maths felt that our so-called 'Mad Experiences' are in the normal scope of people's responses, not an 'Illness' or something outside of human experience. They are well-known in other cultures, with shamans, gurus etc., these different or altered states of consciousness.

Edna: We are sharing the experience of what we are - not what they say that we are. How can we regain our dignity?

Roberta: These sorts of experiences simply go outside of the usual, they are more intense than usual but not abnormal. I am proud sometimes of being extreme.

Lise did not want to speak of normal and abnormal but to have a critical reflective eye in relation to her personal experiences.

Gunnar did not believe in the need to be normal but would actually be sad if he were called normal.

Lars thought that experience depends to a great extent on the culture in which we live. The western culture can seem like a spiritual dead end.

Matthias mentioned that in his group at home the word 'normal' had been used as a term of insult.

Karl Bach considered that some people thought it dangerous for us to define ourselves or give ourselves a label that other people might use against us if they felt they had us taped.

### **Misunderstood *and* mistreated**

To Neil Ward the idea of being misunderstood made a good starting point for discussing the issues of self-definition and self-understanding.

For Karl Bach the way people are seen in relation to psychiatry underlines the misunderstanding which conceptualises us as suffering from brain diseases. Are there reasons for our being misunderstood in this way? We are part of natural mankind, not abnormal. The natural world does not function free and wild within a framework of regulation and artificial 'agriculture'. Human nature is in the same way distorted by values and methods of efficiency and materialism.

Modern agriculture kills the natural in nature. Psychiatry kills the natural in human beings.

Maths said we had to be careful about defining ourselves simply in relation to being misunderstood. Other groups were also misunderstood, youth, for instance. Maybe that was too generalised an idea. We need to look also in a positive way at the experience of suffering, of being in a place in which you did not wish to stay, of moving on, having learned something. He wanted to set the question in relation to society

and to the later question about rights and equity, if we wanted to be different. There are individual differences in every society but it was certainly harder to be different in the post-industrial society. It was necessary to have food, housing and some income or earnings, some money. It was possible in other sorts of societies to live differently, in historical and pluralistic societies for example. In the post-industrial society it was publicly accepted that society had to intervene. The biological and medical model and the labelling of experiences and behaviour of mental illness provided society's justification for that intervention. Being misunderstood was not the key-problem for us; it was being misunderstood and mistreated.

Karl: It's common that we don't think we have braindiseases, but there is a misunderstanding in society that we have braindiseases. If we don't develop our own concepts, our self-understanding - then psychiatry will have the monopoly in developing concepts.

Rasmus believed that being a victim can be a problem in itself. He was uneasy about Neil Ward's idea about our being defined by misunderstanding in case we just accepted that and did not try very hard to change it. It was the role of the European Network to be disputing psychiatric priorities basing the dispute on our understanding of our different experiences. In his view that did not have to wait for some version we could all agree on. There was a great gap between the psychiatric perspective and our individual views.

Edna: Research showed that in many so-called Third World countries the bio-medical model did not have the hold it had in the post industrial society. What is labelled schizophrenia is seen as much less of a problem and less a disruption in the lives of people in non-industrial societies. The power of psychiatry to define needs to be challenged because it is used above all to define those who are most powerless within society, the poor, the unemployed, the black, women, people with disabilities. When we talk of self-definition we must not forget the importance of taking back the power to define ourselves.

Erik O. stated that in his private life he defined himself as a free thinker. It is very difficult to be around us because we challenge the illusions, the assumptions and the ideas of others. It is an illusion that there are not differences. The most common human trait in any nation is diversity. In reality differences are more normal than similarities and equality. Only death is equal. It is good for the community to be aware that society needs people like us who dissent and who do not conform but who question and go to the edge to challenge what normality is.

Jan Dirk thought that some people were not easily understood but why should we understand everything about everybody? We all understand common injustice and mistreatment. This is our common bond - the recognition that that is not the way to treat people. Society has not yet seen this injustice. If they had this experience we have they would need no more explanation, it would be obvious.

What about the idea of adjusting to society? We are always in society, part of it. He spoke of a local group in the Netherlands which this year had won an award for working with the homeless. Sometimes the homeless do not want anything else. They live on the streets. The group accepts that the homeless are not understood but they can still be treated well even if they are not understood.

Eva challenged what Edna had said about madness seeming to be less of a problem in the third world. She felt that in South America and in Africa many hundreds of people were often confined, neglected and abused in appalling conditions.

Edna acknowledged this was so but wondered if this was not partially the result of some of those countries copying the Euro-centric model of psychiatry instead of following their own cultural traditions.

Karl Bach: Some people may see themselves as consumers of mental health services, others as survivors. Can we begin to resolve these differences and find common ground? We all seem to agree here that we do not suffer from brain diseases and we seem to be reaching towards definitions and understandings about

relations with people. In the future we might develop alternatives, so people do not enter psychiatry. The definition of people who have uncommon experiences should not be left to psychiatry.

Matthias wanted to know more about different traditions and ways of dealing with people with uncommon experiences even in Europe, in Finland and Northern Sweden, for instance. One answer for us was to build independent local groups. He knew 25 local groups all very different, none really strong or powerful. Power was key point. Humanity has not been human in history. Only the powerful are treated well. It is a serious fault to leave out the importance of the dimension of power. Just to get to where we are now has taken an enormous effort to get power. Nothing about understanding. The Powerful know what they are doing in order to increase their own riches and power. They define the world for themselves.

Gunnar believed all people need emotional support and if they do not get it they will all become users of psychiatric services. He thought that if one came from a small place where people handle each other with care there is more love and understanding.

### **Should users and survivors unite as disabled ?**

The discussion resumed with Lars saying that survivors and potential survivors need to get together. If there are experiences we have in common they need to be researched and the results published. It would be useful to ask survivors about their expectations. Perhaps survivors could do this for themselves.

Erik believed the problem was that we did not relate well to people who like material things. We are marginalized. The European Union has a Social Charter which does not have much to say about us. But we are not small numbers. We are 20% of the population and we should discuss how we link to other groups.

Matthias thought it was too early to build links with other categories of disadvantaged and disabled people. He knew of 343 such groups in his country, FAPI only had 20 members in a country of 80 million people. There was a lot of work to do. Our Groups needed to get larger and stronger before we could make real contact with other sorts of groups.

Jan Dirk said that links had already been established. Edna as a member of the Helios Group put Roberta forward for the Disabled Peoples' International visit to the European Parliament. There was no money so far for users from Europe while organisations like the DPI could get it. There was a Council of Europe Report on Human Rights in Psychiatry and the All Party European Parliamentary Group.

Mary Nettle asked if we were going to discuss whether what is called Mental Illness is a disability.

Hans said that the only advantage for accepting that was that it enabled us to act politically in the European Community.

Maths wanted us to focus on the development of user- and survivor-groups in Europe. National organisations were developing differently. Northern countries like Sweden, the Netherlands and Britain have larger organisations, other countries are moving forward in their own way. Some others are finding it very difficult. For some people who have been made dependent for many years, dependence may be the only way to survive, We need to take a more complex view of the situation. We need to help people to become less dependent and express their critical views. We need to be a broad group with many views and that includes being practical about people who have no choice and no alternatives allowing time for the growth of consciousness. We need to keep having a dialogue with each other. It is not a bad thing that the German organisations are as they are, going slowly and doing it their own way. Bigger is not always better. You could get many people joining who are not critical of the providers of psychiatry and who want to provide propaganda for them. There is a need to strengthen the belief that it is possible to live without drugs

or even without therapeutic settings. There is a danger that organisations dependent on the current system will end up praising it instead of being critical.

Richard said he did not believe that the only way to get involved politically was under the label of disability. He did not see himself as disabled. If we go that way we become second class even with the disabled. Mental health service users get the chaff at the bottom. What we get will be what the Disability Movement decides what we get. That should be monitored. We should be self-determined. He did not want to be understood but to be accepted as he was. He would only draw a line where it became a question of being a threat to others. Understanding feels good but does anyone understand even her- or himself?

Anne felt it was very difficult to say that one does not need psychiatry or help linked to psychiatry. Lots of people want to help but it may or may not be what we want. She wanted to speak out for the people who say they need psychiatry to have the right to choose, to decide for themselves, to be more responsible for decisions about themselves. It is important for the process that people go on to make treatment and support better. Other people labelling me is their problem.

Karl Bach believed we should consider linking with the disabled not for the money but because we have COMMON INTERESTS. To link with them does not mean we should accept their definitions or use their terminology.

In Denmark youngsters fight for the right to define their own situation. Some disabled people feel that is why we should link. We need the money and the power to meet and for that we may have to depend for now on the DPI and the ERC (European Regional Council of the World Federation for Mental Health).

The problem is not just about small groups working in isolation. When we build our groups we will be able to come out and fight openly. Those who see themselves as consumers are potential survivors, though some are now psychologically dependant on psychiatry.

Mary wanted to go back to the theme of disability. She did not feel she was personally disabled but disabled by society, discounted and devalued, having to lie to get jobs. She shared some of her experience of working with an all-disability group in Wiltshire.

Richard: I feel like a prostitute if I connect myself to the disability-movement to get money and political influence. It's the easiest way, but not the only way to get access to EU. In the disability movement we become second class people. I really don't want to be understood - I just want to be accepted. Disability-organisations really want all to be normal.

Matthias: The disabled people look at themselves with the eyes of the normal - that is ideology in Marx' sense: to see yourself with the eyes of the ruling class.

Jan Dirk said that we had been asked to link up with DPI precisely because we were a user group. It is an international network where they want people who organise themselves. The ERC participates but is controlled by professionals. Other groups which are not run by disabled people also participate. That's why we link up in a political sense to change the balance more towards self-help and self-definition for people themselves. We decide, not others for us. We want user controlled budgets. User controlled budgets in mental health are more difficult to get.

Mary reminded people that there were other groups which faced discrimination apart from the disabled. Each group of people needed first a clear position and a strategy. For instance we needed to find a common name where we could all fit in. We have to decide together what we here should fight for not just everyone fighting for oneself.

Hans: We should stress more on building up alternatives to psychiatry: self help groups. That should be the main topic at our next European conference.

Eva believed we should send a representative to every conference to raise those issues and promote alternative options making them known to professionals and to us. We should make a study of alternatives next year to back this up.

Matthias said in relation to disability that he had his own life and he had chosen not to adjust. If he was in a wheelchair he would have no choice but to sit. He takes his own way and says society has to accept his way. He disagreed with taking the way of the disabled. For him a small group was an important part of consciousness, The supposed view of normals is actually seen through the eyes of middle class dominant hierarchy. Large organisations were often mixed with that.

Edna asked if we did not need both large and small groups. Large groups tend to get too close to the system in order to grow and survive. They can forget where they came from and why. There it is easier to say yes than to resist. It's easier to express anger more openly in small groups. Large groups need the anger from the small groups to keep them honest and true to their original aims. There might be a difficulty about self-help groups who set themselves up as service providers. They could lose their edge and not be self-critical.

Maths said he was not willing to be called disabled. There were advantages and disadvantages in working with them. They always seem to want to be normal. to have a normal life. He could see the positive aspects Jan Dirk saw, fighting together against paternalism. It worked in Sweden because people who support are not masters but assistants.

Roberta said in Britain dis-enabled was a term we could all sometimes use.



## Part two: Self determination and special rights ?

### 2.1. Written contributions from participants

#### 2. 1.a. Self determination:

*How do we achieve self determination in our own social surroundings ?*

*Hans Bergström, RSMH Sweden.*

Self determination means that we should be looked upon as individuals and subjects instead of a diagnosis or objects. We have the right to our history and to our life. That means of course on all levels. We have to brake the power of the white coat in mental care. Because that power also has a tendency to reach out in the society. We as people who sometimes in life need care. support and service should be in focus and not the staff. They are only humble servants.

*Jasna Russo, Boardmember, Yugoslavia.*

If I understood this question correctly, self determination for anyone who has been in the psychiatric system, is about recovering from that experience. And for me, that means first of all getting off psychofarmaca. It also means fighting the stigma; finding sources of energy and self esteem; changing the social surrounding which brought us to psychiatry for the more friendly and understanding one; finding strength for existence which can protect us from further psychiatrisation; working on our personal micro network of friends and people interested who can support us and help us in the next crisis; working together with other survivors and being solidary with them.

*Kerstin Kempker, Berlin, Germany*

How to achieve? By clear refusal to psychiatry. By independent, user-controlled organisations and self-help, by public discussions, publications. (This is how I understood the question.)

*Neil Ward, Survivors Speak-Out, United Kingdom*

Perhaps this is best achieved by each one of us, through a combination of:

- (a) ultimate respect for ourselves. That is to say, who we are -the way in which we work.
- (b) the provision of non-prejudicial information i.e. respect for other viewpoints - even if they are misguided
- and finally,
- (c) make the best use of humour such as satire. This seems to touch the 'human' in humans.

*Theresja Krummenacher, Les Sans-Voix, Switzerland*

The key to self-determination is self-confidence. Once autonomy has been lost, it cannot be regained overnight. But everyone can work on trusting his own judgement and becoming more and more autonomous.

Outside help is generally an asset. Every mental patient should seek an understanding, open-minded doctor, not necessarily a psychiatrist but someone who listens and is attentive to people's problems and needs and who, if necessary, can help the patient free himself from his dependency on psychiatric drugs and can provide alternative treatments.

Self-help groups, humanitarian associations, churches, can all provide moral and practical help and understanding. Legal support is also often necessary to obtain respect for one's rights. Mental patients should unite their forces and try to establish links with progressive doctors, lawyers and human rights organisations.

***Mary Nettle, MINDLink, United Kingdom***

If only we were able to do this! The majority of people who have experienced mental health problems know what is helpful and unhelpful when they have a crisis and are temporarily unable to speak for themselves. The use of crisis-cards and living wills, which are legally enforceable, can only be helpful. There is a need to give people control of recourses to purchase their own care, such as counselling, aromatherapy massage and appropriate housing.

***Stefania Dei, A.I.S.ME, Italy.***

Everyone who has some experience of working, knows it's impossible to reach one's peak every time but the most important thing is never to be discouraged about it.

This thought will always be with us that, in particular, when one cannot manage to do his or her job today it's going to be done tomorrow. A portion of optimism and self- confidence must be kept in the way we behave every day.

***Giampiero Fossi, Gruppo d'Auto-Aiuto Psichiatrico di Firenze, Italy***

How do we achieve self-determination in our own social surroundings?

- Reintegration structures
- Work/job
- Education, teaching (= "normal" social life)
- Professional training

In daily life, there are a lot of difficulties: discrimination, isolation, mistrust and SOLITUDE.

Moreover, a lot of (ex)-users have some crisis periods that produce or increase the chronicity.

Besides, about mental health matters, there are a lot of interests of all kinds:

- economical interests (pharmaceutical industries)
- medical class interests (instrumental utilisation of psycho-drugs, everything to avoid the causes of distress and to protect drug-therapies only for lucre).

On the other side, there are the families that often (not always) do not help the person who has distress. On the contrary, families often lead people to chronicity.

This written report must be a starting-point to reflect for everybody who is involved in the mental health sector. We need to "construct" a better future.

***Lars Jensen, Denmark***

Advice: If you already have been suppressed so far, as your current social surroundings find you fit for psychiatric treatment you do better leave in a hurry - if still able to - live on your own, until you find social surroundings matching your personality - if ever, - if wanted, mutually.

*Marinka Kapelj, SENT, Slovenia*

We mean that we are part of normal society. We need special help, but we expect that this help gives us friends. We don't want to talk about our problems with other people, because we simply want to live without stigma.

*Maija Bäckman, MTKL, Finland (not participating in the seminar)*

Opinions of the Kolding Seminar questions:

In principle in Finland all people have the same legal rights. The laws are in fact good, also to the users and ex-users in Mental Health. Actually we are having conversation about the law of the compulsory treatment care, if it must be changed.

And the parents, who suffer from a mental illness have difficulties to get their rights, before the law taking care of their childrens lives. Despite of these questions, I think that generally the reason is that the users and ex-users are themselves different than others, and therefore they get different treatment and care and also social rights.

We think we are not so good as others, we cannot behave like others, and our ways and customs are different. It is, in other words, a personal and individual way to behave. But because it differs from the usual customs of society and neighbourhood, we get the stigma: deviant.

If we become more conscious of ourselves, and try to get more and more information, we can better live our lives. The most important fact is to work to change our own attitudes and to work to understand better each other, in order to be able to communicate and cooperate. For this we need our national associations and our European Network.

Then we must work hard to change also the attitudes of the environment. But to help and support all the valuable life in hospitals and in non-institutional care, we need also special rights. Maybe the most important right after the economical living is the possibility of work. We need special social rights to give work to everybody according to their abilities, talents and strengths, the work as waged work, sheltered work or occupational therapy.

### **2.1.b. Special rights or just equality ?**

*Should we demand special social rights? If so, which rights would be our priorities?*

*Hans Bergström, RSMH Sweden.*

The goal should be just equality, but it could be necessary sometimes to have special social rights for the most suffering. We have that in Sweden for special housing, work and a right to personal assistance. Some of us don't have the power to demand equal rights so for the time being we should have a special legislation for people who can't stand up for their demands to a worthy life.

The point of our action should remain addressing the responsibility for the difficulties we may experience in finding work, flats etc. We should not step over the fact that psychiatry damaged us, turn the consequences of it into our own disabilities and demand special rights from that position. This is maybe an easier way to cope with life and it's also easier for those who cope with us, but we can never politically fight psychiatry and ask for the special rights at the same time.

*Jasna Russo, Boardmember, Yugoslavia.*

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*Eva Feiglová, Czech Association of Mental Health, Czech Republic*

This question can't be answered in an either/or- way. We need both. Special rights for people who can not yet be integrated back in the society -i.e. protected work and/or living- and possibility to be integrated into the society -working opportunity WITHOUT DISCRIMINATION- for those who wish to work and overcame in the latter the crisis. The reality differs from theoretical laws.

*Kerstin Kempker, Berlin, Germany*

Should we demand **special rights**? No. We should demand common rights: human rights and the right to refuse psychiatric treatment as any other medical treatment.

Imprisonment (without being condemned for a crime), involuntary and uninformed treatment should be forbidden and punished. Psychiatrists should be liable for damages, their victims should get a compensation.

*Neil Ward, Survivors Speak-Out, United Kingdom*

To demand, I think undermines my philosophy. Although the result may be the same, I prefer to approach the question in this way. Yes I believe we are different. Certainly we are misunderstood, breeding intolerance and marginalization from the wider society. Therefore the notion of special social rights is necessary but, not through the demand of these things so much, as through greater education of the facts. It is a fact that mad people are poor. That they are often ill-housed - if at all and finally that, given a minimum level of financial social security and good housing most seek work opportunity, but, that this is almost impossible due to prejudicial practice. These then are the content and order of my priorities which ultimately might lead to changes in social acceptance:

- (a) a minimum level of social security in recognition of our social vulnerability.
- (b) access to safe and secure accommodation.
- (c) equal access to work opportunities incorporating a recognition of our vulnerability

*Krzysztof Paszek, 'PSYCHE', Poland*

In my opinion it is necessary for people who have mental problems to have the same rights as others. We don't need special rights to live humanely. The fact that we have mental health problems does not indicate that we are better or worse than other members of our society

More important for us is understanding our problems and fighting rights which other people have - e.g. pregnant women, invalids, unemployed people -. We don't live alone, so we need to cooperate with the others, work together.

We need the following rights:

- The right to proper protection during the illness
- The right to have a possibility to chose different treatments

The right to have advocacy protection

The right to have a possibility in organising our community in lobbies and associations

The right to have social protection in difficult moments - work in special workshops, set up hostels, use money from foundations for social projects .

Generally we need possibilities and rights to carry about our lives ourselves. This all is for me equality and we should demand these rights.

In many cases people don't have even those rights. Helping others does not indicate something special. It should be normal. This all for me means equality.

***Theresja Krummenacher, Les Sans-Voix, Switzerland***

Equality is a sine qua non. But there can be no equality without recognition. Mental patients should sit in all public consultative and decision-making bodies concerned with mental health, as well as on the boards of administration of the psychiatric hospitals, community institutions etc.

As to special rights, if society mistreats mental patients, subjects them to degrading and dangerous treatments with long-term consequences, it must necessarily assume the consequences of its acts. What might be termed special rights can also be regarded as normal compensation for the damage done.

We consider it a priority for society to provide appropriate medical and social care in adequate surroundings. We feel there is a dire need for alternatives to psychiatric hospitals in the form of community institutions (temporary homes, day-care centres) where persons can go to in case there is a crisis or the risk of a crisis, where they can "run-away" to, where they can go to when they have been released from a psychiatric hospital.

It would also be useful to have teams of "friendly helpers" who could keep company to patients in their own homes and by their reassuring presence could alleviate a patient's anguish and worries.

***Mary Nettle, MINDLink, United Kingdom***

I do not believe that special rights for the mentally ill would be helpful but I do believe in special rights including anti-discrimination legislation for people with disabilities. In this way those people with mental health problems who consider themselves to be disabled would be given special rights. However we must demand equality particularly an end to special laws which force us to receive 'treatment' for an indefinite time against our will.

***Stefania Dei, A.I.S.ME, Italy.***

Should we demand special social rights (e.g.. work, housing, money?)

If so what rights would be our priorities?

The most important thing for us is having a job. It is of great use for our individual daily means of support, but it is important because we can get in touch with other people, so-called normal fellows, and strengthen our individual personalities. Therefore it would not be a job set up by a co-operative firm otherwise it's possible to set up a new ghetto. This job has to be found in the fields of private firms or within public authorities.

Certainly the job must be congenial to our cultural and intellectual faculties. It has to start gradually, firstly two or three hours every day, then it would go on to be a full-time job with a good salary so one person can live in a dignified way. This job has to meet the disabled peoples' requirements during his or her working time.

The second thing is to have some easy terms of payment in order to have ones own house or flat.

***Giampiero Fossi, Gruppo d'Auto-Aiuto Psichiatrico di Firenze, Italy***

Equality. We need obviously an adequate assistance and above all a preventive action in this sector. It has no sense talking about special rights. We can avoid several admissions to hospital, if we had right opportunities. So, it would be really possible to become self-sufficient and self-reliant, capable to face the life with all its difficulties joys.

***Lars Jensen, Denmark***

Society's defining you lunatic, blocking your access to income and forcing you to live extremely marginalized should release special rights and compensation in any and all aspects of the so defined handicap.

The domain of psychiatry is the battlefield of modern civil war.

***Marinka Kapelj, SENT, Slovenia***

A lot of people, who were in psychiatric hospitals don't have jobs and/or housing. Of course they don't have money either. When they are in hospital a long time, they don't know to work anymore. Employers have usually refused them. Therefore we need the special rights for our people that they can get jobs, but later they are working like others. In Slovenia the law provides a chance therefore. It will be necessary that we have the law for the housing too. But we have not. Therefore in our organisation we have prepared the group home. If our people work, they have money, and we think that we don't need special right for getting money.

## **2.2. Plenary session**

Neil: (Reporting from the group) It was agreed that we are not different from average citizens but perhaps have some disabilities. There should be certain social security systems, e.g. for housing, so we have more chance to be treated in an equal way.

Jan Dirk: Most important is the possibility to choose - also to choose the wrong things, to take risks. You should only be punished if you have done a crime - and not for prevention.

Karl: Self-determination is the possibility to influence the surrounding - to build up subcultures (like our house here in Kolding).

Maths: I'm a bit sceptical about community-run day-centres. The staff there often tries to get the users very dependent on them and do not let them know any alternatives or how to get back to normal life. The staff at the community-centre is always afraid to loose their jobs - and therefore need to have as good statistics of the number of visitors as possible. There is a danger that people because of this can be made very dependent on the house.

Edna: In San Francisco there are two user-run drop-in centres. One is very structured, but it is also run by few of the users. In the other one, in Berkley, there is no structure and no order, but a great warmth and a sense of belonging.

Neil: There is a conflict between successfully user-run drop-in centres and authority-run. They can't understand our language, so they withdraw the money.

Richard: About dependency: I may choose to be dependent. I don't like the psychologists use the word "dependency". One man's dependence is another one's choice.

Erik: You can also have small shops and work together with others, like the small co-operatives in Italy.

Lars: It's important also as a user or ex-user to be a political activist, because we have to influence society and not to just build subcultures.

Maths: To be able to choose presupposes that there are alternatives. Otherwise you can't choose to be dependant neither. Therefore society must make it possible also to have support to live in a home of your own, to work at an ordinary workplace and to go into the educational system. They should not just tell you: there is a group-home where you can live and a day-centre you can visit all day long.

Jan Dirk: We have to make what we are talking about into a human rights issue - which is for all human beings as these problems can happen to everyone.

Karl: If you say that you are like everybody else, why should you have a social pension? We must talk theoretically and generally about policies, because if we make the wrong choices perhaps a lot of users in Europe think that we are just talking about ourselves - while they at the same time are starving, are without houses etc.

Jan Dirk: We must not be political in an ideological sense, but of course we must be lobbying.

Maths: If we want some special rights, different from average citizens, we must also discuss which criteria there should be for obtaining these special rights and who should decide about this.

Edna: Community mental health agendas talk about services - but user agendas talk about personal needs. You cannot separate special rights and equality from quality of life. We need special rights to get equality.

Rasmus: There should be a basic income for all people in society.

Roberta: There are projects where the user decides how to spend the money: to use the money to go to a university conference or to clean the house. There must be a possibility to live in society out of the mental hospital.

Richard: There should be an equal opportunities legislation in UK. The criteria should be: current or previously using of the psychiatric services. Then people should have the right to apply to local committees. People with a short stay in psychiatry will probably not define themselves as "a previous psychiatric device user" when for example applying for a job.

Edna: Our national projects have changed something. But every time anything has gone wrong there is a moral panic in the media - and they don't interview users but relatives and professionals, who ask for more involuntary treatment.

Neil: I don't try to convince them, but to tell them that they don't understand.

Lars: I want us to discuss if we should be an organisation like Amnesty, supporting individual survivors?

## List of participants

Czech Republic	Eva Feiglová
Denmark	Anne Mette Jacobsen Karl Bach Jensen Lars Jensen Erik Kristensen Lise Ladegaard Michael Maagaard Gunnar Mathiasen Erik Olsen Rasmus Skotte Gerda Buch-Larsen (secretarial assistance)
Finland	Liisa Pakolanvaara
Germany	Kerstin Kempker Jasna Russo Matthias Seibt
Italy	Stefania Dei Giampierro Fossi
The Netherlands	Jan Dirk van Abshoven Wouter van de Graaf
Poland	Krzysztof Paszek
Slovenia	Marinka Kapelj Igor Spreizer
Sweden	Hans Bergström Maths Jespersen
Switzerland	Theresja Krummenacher
United Kingdom	Richard Butler Edna Conlan Roberta Graley Mary Nettle Neil Ward