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# Capacity of the psychosocially disabled's organizations in Europe

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Research Proposal

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*The slogan "Nothing about us without us"  
only have real meaning if people with  
Psychosocial disabilities/mental health  
problems themselves have  
organizational strength to reflect about  
their situation and thereby have a voice*

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# Research Design

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## *Purpose of research proposal:*

The aim of the research is to understand and enhance organizational capacity for the collective representation of psycho-socially disabled people in Europe. Using participatory and consultative methods, the research will document and assess the capacity of existing organizations to represent the voices and interests of psycho-socially disabled people. In this context, it will focus on the capacities and strategies of:

(a) Representative organizations controlled by psycho-socially disabled people; (b) traditional 'mental health' organizations; and, (c) national disability umbrella organizations. The main questions addressed by the research are, therefore:

1. What types of organizations exist to represent the voices and claims of psycho-socially disabled people in European countries, what resources are available to different organizations, and to what extent are they democratic and representative?
  2. How do psycho-socially disabled people, within these organizations, position themselves in relation to the political discourses, identities and claims of disabled people's organizations?
  3. How can the collective claims of psycho-socially disabled people be most effectively represented in European countries and at the European level, and what resources are required to build that organizational capacity?
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The overall purpose is to get reliable data on the degree of inclusion, equality and empowerment of psychosocially disabled are facing in a given time and to produce new knowledge that will qualify action.

Its purpose could also be seen as investigating the social reality seen from the psychosocial disabled point of view. There are many different voices in the mental health field as well as in the political area about this group of people in political areas at local, national and European level.

How strong are the psychosocial disabled? There is a lot of interest from all sides about people with mental health problems- and it seems as if there is some kind of consensus about how to act. But to what degree have the psychosocial disabled a say in this? There seem to be agreement at European level about:

Inclusion, empowerment, mainstreaming, non-discrimination, human rights and so on...

But how do people with mental health problems see themselves among all these other voices?

In providing an oversight of the psychosocially disabled organizational capacity, it will probably for the first time be transparent for policymakers, public disability organizations to formulate a cohesive and sustainable policy at European, national and local level. Analyzing the data will provide clear oversight which can be used in implementing measures to counteract discrimination, build up empowerment programs and even point at solutions for public mental health policy at large in Europe.

Years of work to implement user participation can find new ways and more important the basis for building partnership around mental health, disability can be done in national and European frameworks.

For the psycho-socially disabled them selves this could be a new starting point for their recovery, empowerment and real sustainable inclusion would be possible.

For the Academic world this could be used to further research and promote building research capacity as a first step towards building universities in mental health at European level.

Disability has now emerged as a significant dimension in understanding European citizenship, social exclusion and equality yet there is an almost complete absence of systematic comparison grounded in the real life experiences of disabled people themselves.

By providing an oversight and by involving psychosocially disabled in research it will be possible in the future to include the voices of people with psychosocial disabilities themselves in the design of needs provision, strategies for inclusion and new ways to deal with disability in these areas. People with mental health problems or not visible disabilities are not seen as people who can speak for themselves- professionals, physicians, relatives and many other speak on their behalf. The cost and efficiency of funding others to speak for psychosocially disabled are immense and the solutions they provide reflects in many ways more the need of themselves. In the light of equality this is a serious problem.

By doing this research monitoring and building up the capacity of the disabled own organizations their own capacity to have a voice would mean a huge difference.

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## *Research Partners*

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I suggest that the research would be a collaborative research between EDF- European Disability Forum, Leeds University for Disability Studies and ENUSP European Network of Users, X-users and Survivors of Psychiatry, or maybe ENUSP and Mental Health Europe as a Partners – it would be Leeds, EDF and MHE/ENUSP .

All these Stakeholders have a common interest in the research I think and could provide crucial knowledge and data.

About EDF involvement: The research design could be constructed so it was possible to transfer the design and implement it in the future - to other disability areas. The degree to which other disability organizations are either run by other than the disabled themselves or their voice are weak, compared with others, are probably quite diverse and implementing a transferable research could make future comparisons between different groups of DPO organizational capacity – meaningful and possible.

## *Methods*

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The methods would be using internet based surveys combined or supported by telephone to get the most precise data around the basic measuring of basic capacities such as organizational, economic capacity and to a certain extent political issues.

MHE has made some kind of research before but this has to be made again.

There would be a division of responsibilities between the research partners.

Leeds would provide the scientific support and parts of its execution, MHE could be responsible for the administration and ENUSP could together with Leeds perform the participatory part of the research.

Estimated time frame 2 -3 years

If its mainly based on EU funding it might be only all EU countries where the atlas of how and what capacity psychosocially disabled organizations capacity are.

Note: The way psychosocially disabled are organized in own organizations in different European countries are very diverse going from national organizations like MTKL in Finland which consist of 25.000 members and a vast variety of local member organizations. Through Denmark where there are one national only disabled run organization and one big Mental Health organization. To England and Scotland where there are many different and competing organizations both at national and local level.

In Scotland the Government have recently help users to form a national user organization (VOX).

Then again there are scarce and different ways to organize in South European countries ranging from Spain where the family organizations are the only one at national level and Italy where users organize in small self help groups .

The former Eastern Europe has different organizations initiated by Hamlet Trust – but some countries are only represented by a single user.

Another challenge is that there are tendencies that pharmaceutical companies and psychiatrist helps psychiatric users to organize in accordance to diagnoses. But to include these in the research at this stage would be a challenge.

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## *Reliability.*

In the quantitative part of the research there are questions about reliability that have to be answered.

The research will be conducted as a questionnaire to document the capacity of disabled organization compared with mixed mental health organizations and an analyze of “user-organizations access to national Disability organizations.

The method is a combination of telephone interview and web based survey.

The first problem is to determine which organizations that should be investigated. There are today, not an atlas of psycho-socially disabled own organizations in Europe.

Therefore a preliminary research has to be done, to see which organizations should be included.

When this is done, there are other considerations. How can capacity be compared between different EU- countries? There are differences in living standard, culture and so on...

It's probably more secure to make comparisons inside each country, but if there are going to be comparisons between countries – a set of weighted references have to be made. For instance – economical strength could be weighted through % of average GNP per person.

The answers reliability could be better if it was possible to make cross- over validation of the answers between stakeholders, public funders, data from government etc...

## *Validity*

If the research are done by disabled persons themselves, there could be a better chance to receive data in the first place from the disabled own organizations. The opposite could be true with MH organizations if the approach is seen as a challenge to their influence in the area..

But the data should be constructed so that other researchers will be able to repeat the research and validate the results.

To sharpen the questions, there have to be maybe, several “pilot” surveys- where the questions are tested to see if they are meaningful, understandable, and precise –

There are differences in language – some concept is not the same in different languages – the way to deal with this are probably to facilitate two-ways communication.

There have to be feedback possibilities, to correct or talk about the concepts or questions.

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*Sketch of possible questions  
(have to be elaborated in partnership and pilot tested)*

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**Organizational questions**

What is the name of your Organisation?

Which type of organization?

(boxes)

What year was the organization started?

Is it a National Organization?

Do you have local /regional branches?

Do you have membership?

How many members do you have?

Who can be members?

(boxes)

What type of democracy do you have?

Do you have a board ?

If yes, have many and how many are Users?

At the general Assembly – is it only users that can vote?

## **Economy**

What is the total budget per year?

Where does the money come from?

(boxes)

How much is the expenditure budget?

How much of the total budget comes from project funding??

Are you full members of the National Umbrella organisation for Disabled?

If not – why?

How many works as volunteers?

How many are employed with wages?

Size of the organisations localities ?

## **Political questions**

What do you think is the 3 most important political issues you work with?

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## *“THE SOCIAL DIMENSION IN EUROPE IN PERSPECTIVE*

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*Seen from the psychiatric users perspective I need to shortly sketch where we are in the late history from around 1970'ties up to now, seen from the psychiatric users point of view.*

*The changes that have we have noticed can be divided in three group*

### *FROM ASYLUM TO THE STREETS*

*In the 60'ties and 70'ties people with mental health problems where “looked after” mainly by their parents or big asylums. When de-institutionalization started, we were thrown out of the asylums and a lot of us ended in the streets as homeless .Not much was provided to help us in this first era .*

### *FROM STREETS TO COMMUNITY SERVICES*

*The next period from late 80'ties up to around the millennium– there were built or established a wide range of services in the community.*

*We were accepted and tolerated if we did not blend too much with the surrounding society.*

*We call it – the building up of Reservations where we where IN the society but not where allowed to play a significant role.*

### *FROM COMMUNITY SERVICES TO THE LABOUR MARKET*

*This is the latest development in policy toward the mentally ill.*

*After a consensus in EU, -The Social Dimension of EU – the EU policy goes in direction of inclusion of all the people that are outside the labor market, especially those that are on passive benefits. EU cannot compete with USA and Japan when EU has so many on passive benefits*

*The Renewed Lisbon treaty shall also be seen in this light.*

***We call this an opportunity for us to not only be in the society but also the possibility to play an important role in the Society.***

*Richard Warner (1997) tells us in his book Recovery from Schizophrenia- Psychiatry and political Economy , that the Recovery rate through the twentieth century seems to follow the conjunctures of the market. It's more easy to recover when there a high conjuncture because the labor market tends to open up –*

*In the user movement I have supported the concept of Recovery – pragmatic - because it opens the possibility for improvements for the general user – but we are aware that there are also dangers with inclusion if it is driven by market mechanism only.*

*First of all we do not accept only to be used as a “buffer” where we can be used as labor one day and when the market drops we are the first to get fired. We need sustainable jobs.*

*But the other point here is that I will never endorse a person with severe mental health problems to get a job if it reduces his life quality. As everybody probably knows the biggest contributor to bad mental health is the labor market.*

*The cost for EU where 263 billions of euro in 2002 – because of stress and depression in connection with the labor market. (WHO statistic)*

*In my view we have to use some of the same tools as UN and others use when dealing with underdeveloped countries – Empowerment through building up this underprivileged group inside the European countries by giving them the agency of freedom to act themselves and this by providing the necessary funding, gifts and investments in them as a disadvantaged group. “*

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