

# FROM OUR POINT OF VIEW



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ISBN 978-91-984743-6-7

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Photos: Lovisa Schiller (page 7) and Lisa Ringström (page 14).

Other images are taken by Thomas Henrikson.

Production and printing: EO Grafiska, Stockholm 2018

**”We see ourselves – patients, users and next of kin – as a resource that is both essential and indispensable for the development of health care, support and treatment in society.”**

# This is NSPH

The Swedish Partnership for Mental Health, NSPH, is a network of organizations for patients, users and family carers in the mental health field, a term which is used in a broad sense<sup>1</sup>. Our aim is to work together so that patients, users and family carers will have a greater level of participation in the healthcare and support services and gain a greater influence on the decisions that are made at various levels in society.

Our membership organizations each work with their own focus within the mental health field and thus with their own lobbying. We collaborate in joint lobbying activities in situations where it can be more effective when speaking with one voice.

NSPH thus focusses on issues, where by working together, we can be heard more clearly and have a greater knowledge base than each separate organization. These issues include: user influence, more patient-centered care and systematic quality improvements within the health services. This has been a core feature of NSPH's work since it started in 2007. Strengthening both national and regional networks, with the aim of increasing the pressure for participation in the government's continued endeavors in the mental health field, has been a major focus the last few years. An increasing

number of regional networks or associations have been established and NSPH is now represented in many strategic development forums, both nationally and regionally.

The collaboration within NSPH originated in 2003-2006 during the work carried out by the national coordinator for mental health. The organizations, who represented patients, users and family carers in the mental health field, met under the auspices of the national coordinator. After the completion of the national coordinator's assignment a desire was expressed to create a more long-term and permanent collaboration. The result was the establishment of NSPH in 2007, the Swedish Partnership for Mental Health, which subsequently became a non-profit membership organization in January 2017.

We work closely with Hjärnkoll, the Swedish program against stigma, which was formed by the organizations within NSPH. Hjärnkoll's assignment, which is to be carried out through their ambassadors, is to work for the development of and dissemination of knowledge about what it is like to live with mental ill health and to reduce negative attitudes and discrimination towards people with mental ill health.

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<sup>1</sup> The mental health field in a broad sense entails the health authorities' hospital-based and community-based psychiatric healthcare, related municipal social services, work rehabilitation, schools, education, services for children and young people, prison services and other public agencies.



#### **FMN, Föräldraföreningen Mot Narkotika**

– The National Swedish Parents  
Anti-Narcotics Association  
[www.fmn.se](http://www.fmn.se)

#### **Frisk & Fri**

– Healthy & Free – eating disorder  
charity  
[www.friskfri.se](http://www.friskfri.se)

#### **RFHL**

– The Swedish Association for Support  
to Pharmaceutical and Drug Users  
[www.rfhl.se](http://www.rfhl.se)

#### **Riksförbundet Attention**

– The Swedish National Association  
Attention  
[www.attention.se](http://www.attention.se)



#### **Riksförbundet Balans**

– Swedish national association  
for people with depression, bipolar  
disorder and their related  
[www.balansriks.se](http://www.balansriks.se)

#### **RSMH**

– The Swedish National Association  
for Social and Mental Health  
[www.rsmh.se](http://www.rsmh.se)

#### **Schizofreniförbundet**

– Swedish Schizophrenia Fellowship  
[www.schizofreniforbundet.se](http://www.schizofreniforbundet.se)

#### **SHEDO**

– Self-harm and eating  
disorders organization  
[www.shedo.se](http://www.shedo.se)



#### **SPES**

– HOPE  
[www.spes.se](http://www.spes.se)

#### **Suicide Zero**

– Suicide Zero  
[www.suicidezero.se](http://www.suicidezero.se)

#### **Sveriges Fontänhus Riksförbund**

– Swedish Clubhouse Coalition  
[www.sverigesfontanhus.se](http://www.sverigesfontanhus.se)

#### **Svenska OCD-förbundet**

– Swedish OCD Association  
[www.ocdforbundet.se](http://www.ocdforbundet.se)

#### **ÅSS – Anxiety Disorders**

Association of Sweden  
[www.angest.se](http://www.angest.se)

# Foreword

Mental ill health<sup>2</sup> is an area still characterized by negative attitudes, prejudice and a lack of knowledge. We, who have worked with these issues for many years have, however, noticed that some things are taking a turn for the better: more and more people understand that patients, users and family carers are to be included in the development work that is in progress within the mental health services. There is a greater openness and acceptance concerning mental ill health, which reduces prejudice in society. In spite of this progress, there is still a lot to do and this is where NSPH can make a difference. We can contribute with our knowledge about different development processes and put pressure on and make demands on policymakers, decision-makers and health authorities. We are convinced that there will be better results if people with experience of mental ill health can participate in the decisions that are taken, both those taken on a daily basis in healthcare and social services and those on an overall strategic and political level.

There are thirteen organizations of patients, users and family carers within the mental health field within NSPH. We represent different diagnoses and conditions but have a great deal in common. We are not a small minority advocacy group and do not represent a narrow special interest, but instead

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2 With the term mental ill health, we mean both mental disorders and psychiatric disabilities

a large proportion of the population. Mental ill health is common and in Sweden three out of four people have own experience or experience of being a family carer to someone who lives with mental ill health. The National Board of Health and Welfare have calculated that 20-40 percent of the Swedish population have mental ill health and according to the Social Insurance Agency it is the most common cause of sick leave.

The list of things that we in NSPH want to achieve is long. Our demands cover everything from better healthcare for individuals to systemic and societal changes that can prevent and alleviate the negative consequences of mental ill health. In this brochure we present the overall aims and positions that we have arrived at during the ten years that we have collaborated.

We also work with more specific projects and issues that we consider to be of great concern. We help to develop and spread methods for achieving participation, user influence and quality improvement which we think that the healthcare and social services should use to a greater extent. We are also active in issues that concern the training of staff, service guidelines and directives, formation of legislation and the authorities' interpretation of them.

We produce our own study material and handbooks, we collaborate with adult education associations, authorities and healthcare services, we give lectures to staff in healthcare and social care, we participate in meetings and at conferences. We invite both politicians and those with their own experience of mental ill health in order to understand what needs to be done and how we can influence the community in the direction our member organizations wishes.

Mental ill health in society is on the increase and children, adults and the elderly all suffer. There is no single person who alone has the solutions needed to buck the trend. Everybody, who wants to work for better mental health, needs to contribute if we are going to be successful. We believe in the strength developed in collaboration, both within our network of membership organizations and with other actors.



**Anki Sandberg,**  
chairman of NSPH

# NSPH's aims



Enhanced recovery and more empowerment.  
Equitable conditions for living a good life for people with mental ill health and their family carers.

Good quality health and social care, based on science, proven experience and the individuals' experiences and self-will.  
A health and social care that is easily accessible, equal, democratic and legally secure.

A society without prejudice, violation and discrimination, which counters mental ill health as far as it can be done.

# The way we work

## We produce and spread knowledge and tools

We continually replenish our knowledge-related toolbox with methods for how patients, users and family carers can equip themselves to be able to and dare to exert influence, for how to support each other and how to collaborate with staff and decision-makers in order to develop, monitor and ensure quality assurance regarding both individual assistance and whole services.

We do our own enquiries and spread information and studies of the health and social care and living conditions for patients, users and family carers. We cooperate with healthcare and support services in order to develop and spread methods that create influence and a higher level of quality.

## We support regional collaboration

Associations for patients, users and family carers in the country often form networks to pursue common issues both locally and regionally. At the national level, NSPH provide support to the associations who want to collaborate on a regional level. It is not uncommon for us to support the local associations and their municipalities and health authorities to develop forms of cooperation that suit their needs and circumstances.

## We have a dialogue with authorities and other national actors

We organize conferences and seminars that focus on NSPH's core issues and also participate as lecturers, exhibitors and co-organizers in activities that other actors take initiatives for. We participate on a regular basis in a large number of reference groups, steering committees and workgroups. The invitations come from authorities, government ministries and other national actors. NSPH are engaged in joint lobby activities, by formulating comments on official reports and inquiries as well as approaching government ministries and authorities to raise issues that we consider need to be highlighted or developed.

## We communicate our work and spread our messages

We arrange conferences and seminars about NSPH's central issues. We participate with lecturers and exhibitors as well as function as co-organizers in activities that others initiate. We write debate articles and share information about our operations and our positions in publications, study materials and in social media.



# Living with mental ill health

Living with mental ill health is not merely concerns regarding health and social care. It is first and foremost about living one's life in companionship with others. A life that contains freedom, participation and the same possibilities, rights and demands as for other people in society. This means that housing, work, income, family and friends to socialize with are the core elements in life. Many studies show that the lack of these basic conditions leads to mental ill health and causes difficulties in recovering.

Fear and ignorance leads to people finding it difficult to speak openly about mental ill health and isolate themselves or be isolated by others. We, in NSPH, work together with Hjärnkoll to achieve greater openness about mental ill health and a greater understanding for people's diversity. The aim is for everybody to have the same rights and possibilities, regardless of the way they function mentally.

## Health and longevity

Mental and physical ill health often augment each other. It is an even greater challenge to build up and maintain one's physical health for people with both mental ill health and addictive disorders. It is well-known today that people who live with a serious mental illness, mainly schizophrenia, schizotypal disorder and bipolar disorder, risk living a considerably shorter average life; men risk

dying 15-20 years earlier and women 10-15 years. The National Board of Health and Welfare have also shown that people with a psychiatric diagnosis who also live with a physical illness such as stroke, breast cancer, diabetes and heart attack do not receive as good medical care as those patients who do not have a psychiatric diagnosis.

## Economy and work

People with mental ill health have considerably lower incomes, higher living costs and a shorter education in comparison with the rest of the population. Furthermore, they suffer from loneliness and isolation to a greater extent than others. Many are just not capable of overcoming a difficult life situation. The association between a bad financial situation and mental ill health is strong. Reports from The National Board of Health and Welfare and figures from Statistics Sweden have shown, for several decades, that people with psychiatric disabilities have a weaker financial standing than people with other disabilities. Those with psychiatric disabilities who are employed earn less than half as much as the average national wage.

A bad financial situation and worry about future income makes recovery more difficult, which in turn makes it difficult to cope with education and work as well as securing an economically stable situation. It easily becomes a vicious circle that is

difficult to overcome by oneself. A further obstacle to breaking isolation and stigma is that it often costs money to participate in organized activities within sports, culture and outdoor life.

### **Negative attitudes and discrimination**

In spite of the fact that mental ill health is common, many of those who suffer feel ashamed and find it difficult to share their experiences with others. Many choose not to talk about it at work, in school or in their social lives. And many of those who have spoken openly about their experiences have felt that it has led to them being unfairly treated both in their private lives as well as at work. To be – or to worry about being – discriminated can lead to individuals abstaining from applying for work and education that they feel qualified for or from joining social contexts that they would like to be a part of.

NSPH, with funding from the Swedish Inheritance Fund, ran an advisory service 2014-2017 for people who felt they had been unfairly treated due to their mental ill health. The most common reason for seeking advice, among the 450 people who contacted the service, was that they felt disadvantaged in their contact with the mental health services (23 percent) or with the social services (22.23 percent); these are thus the two agencies that have the ultimate responsibility for promoting mental health and safeguarding people's basic living conditions.

### **Compulsory care**

Good care is based on an alliance between the individual and the care provider. The patient and the family carer need to feel secure and be able to trust the healthcare services. Coercive measures lead to experiences that take a long time to work through. When the mental health services work more systematically to avoid coercive measures, these can then be reduced considerably. If time and effort is put into allowing staff and patients to follow up and evaluate the compulsory care that does still take place, then this can contribute to greater knowledge and prevent similar situations occurring again.

### **When the healthcare is inadequate or causes harm**

There is explicit and comprehensive legislation that protects the right of the individual to receive good health and social care, where information, continuity and influence are essential components. If, however, someone has been badly treated, been given inadequate information or suffered direct harm due to the treatment and services, it is difficult in practice to lodge complaints, find new care providers, be offered other treatment, compensation or to receive redress.

### **The family carer's situation**

The person who lives close to someone who suffers from ill health wants to be supportive; by

contributing with knowledge and by being an asset when treatment and services are formed. Instead, the family carers often experience that they have to step in when healthcare and other services do not function as intended.

In 2015, NSPH conducted a study among family carers to people who were affected by mental ill health. Many of the respondents spoke of a vulnerable situation with persistent worry for the one who was ill. A majority had stopped working, reduced their working hours or changed jobs in order to be able to support their relative in their daily lives and contacts with the healthcare and social services and other authorities. Almost half of them had been on sick leave due to what being a family carer entailed for them. Approximately only half of them had been offered any form of support and most of those who had been offered help were quite dissatisfied with the support and felt it was uninformed and inflexible.

The issue about the family carer's situation is also one of gender – it is most often a mother, wife, sister, mother-in-law or female friend who shoulders a heavy responsibility when the coordination of various care services is inadequate. A clear majority of the participants in our study were women. There were 1 393 in total, while only 83 were men.

## Accessibility and coordination of services

The healthcare and social services and other welfare systems face major challenges. It is difficult to recruit staff with the right qualifications. People expect access to a wide range of services and treatment that is based on the latest knowledge and that can be adapted to one's own conditions, irrespective of where one lives. The person who seeks help wants to feel that they are welcome and acknowledged, to understand the potential effects of different treatments and to feel that it is possible to have a constructive dialogue with the professional staff about which treatment would be the most suitable. People with mental ill health often need support from several different authorities and public services – and expect that these can cooperate with each other and coordinate their services. They want to be able to meet highly qualified personnel with up to date knowledge in a system that generates continuity and secure relationships.



# ”Nothing about us without us” – more influence on all levels in society

It is not just health and social care that need to be changed in order to address the issue of mental ill health in society. We want the whole of society – schools, working life and the civil sector – to contribute to both preventing ill health and carrying out the necessary adjustments for those living with disabilities or are recovering from illness. More people with their own experiences need to participate in and contribute to these social changes so that we can successfully achieve these aims together.

People with their own experience of ill health must be allowed a voice on all levels in society if authorities and other public services are going to be able to make wise, long-term priorities. Furthermore, aims must be formulated and monitored from the perspective of those with their own experience so that we can see whether a measure actually works towards achieving the aims we are pursuing.

We think that, irrespective of what is done to prevent, alleviate or cure mental ill health, the services must be founded on science, the

knowledge of the professionals and those who in different ways live with our own ill health or with someone close who is ill. This does not just concern the treatment or services for an individual – it is also a basic principle that must be applied when officials and politicians make decisions on higher levels in the fabric of our society.

## Individual influence

For the individual it is a case of participating in, deciding on and influencing the shaping of the services that society can offer. The legislation in this field is very clear but nevertheless it is the lack of participation and continuity that is the most common complaint among patients, users and family carers in the psychiatric area. We feel that the individual’s possibility to exert influence is important for democracy, the individual’s health, recovery and empowerment as well as for maintaining quality in the services provided by the society.

**NSPH thus works for:**

- increased utilization of methods that strengthen dialogue and that involve the individual in active planning and monitoring
- constant pursuit of reducing the need for compulsory psychiatric treatment and coercive measures
- making it easier to present complaints about the healthcare services, change care provider and receive redress and compensation for harmful and inadequate care

**Influence for groups of patients, users and family carers**

The possibility to exert influence on a group level is important for being able to focus on what the groups, who are in need of support, feel is necessary and effective for them. It generates a better ground for those making the major decisions about resources and priorities and about the staff's competence development. For example, it can concern what the attendees at activity centres themselves think about the set-up and development possibilities of the service or how the staff of one health authority gain knowledge by listening to and learning from the experiences of a particular patient group.

**NSPH thus works for:**

- municipalities, health authorities and other authorities to be better at monitoring the results that are important for patients, users and family carers
- more patients, users and family carers to participate in the evaluation of and improvement of the quality of public services
- the public services to create positions and functions in the health and social care services<sup>3</sup> that are based on the unique knowledge that people with their own experience of mental ill health possess as an integral part of their quality development work

**Influence for the organizations who represent patients, users and family carers**

If influence and participation functions well at the individual and service levels, then there will be greater possibilities for our associations and organizations to hold constructive and development-oriented dialogues with the public officials and politicians responsible for the controlling the services for people with mental ill health.

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<sup>3</sup> For example, peer supporters, user influence coordinators, mentors and coaches

**NSPH thus works for:**

- the managers of the public services to be better at monitoring the needs of the target groups and the services' results from the perspective of the users
- more patients, users and family carers to commit themselves to working with advocacy
- the associations who want to contribute to development work can receive the resources that are needed to collaborate and to have an influence and that their representatives receive proper compensation for their work



# Do you want to know more about our tools, knowledge, suggestions and opinions?

You can access NSPH's analyses and opinions on [www.nsph.se](http://www.nsph.se) as well as downloading or ordering our reports, knowledge reviews, study circles and other educational material.



# The reasoning in "From our point of view" are based on knowledge from the following enquiries

- The minus account – financial conditions for people with psychiatric disabilities (Hjärnkoll and NSPH)
- Who helps the one who helps? (NSPH)
- Discrimination in connection with mental ill health – an overview of the knowledge (NSPH)
- Somatic care and illness concurrently with mental disorder (National Board of Health and Welfare)
- Experiences of discrimination among people with mental ill health (Hjärnkoll)
- Mental ill health – attitudes, knowledge, behaviour (Hjärnkoll)

# ”Nothing about us without us”

Swedish Partnership for Mental Health, NSPH, is made up of a network of organizations for patients, users and next of kin within the mental health field.

In this publication we tell more about our vision, background and activities. NSPH works for increased participation and greater influence over decisions made in different areas of society that concern people with mental ill health experience.



*Swedish Partnership for Mental Health*