

# Personal Representative Service in Sweden for People with Mental Dysfunction

Sonia Nilsson

Development Leader, Central Stockholm Psychiatric Unit, Sweden

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## Summary in Swedish

1992 föreslog Psykiatriutredningen att personer med allvarlig psykiska funktionshinder skulle ha rätt till ett personligt ombud. År 2000 togs beslut om statsbidrag till kommunerna för att bygga upp och utveckla verksamheter med personligt ombud. Socialstyrelsen utfärdade riktlinjer gällande de personliga ombuden, målgruppen, organisationen och arbetsuppgifterna. Regeringen hade gett i uppdrag till Socialstyrelsen att leda och samordna arbetet.

Servicen skall vara tillgänglig för personer över 18 år som har en psykisk störning med långvarigt socialt handikapp och komplexa behov av vård, stöd och service.

Arbetet inkluderar rollerna som "mäklare/samordnare" och "advokat". Alla beslut skall tas av den funktionshindrade och allt arbete skall vara baserat på individuella behov. Det personliga ombudet skall inte varvara i den position att han/hon tar beslut enligt Socialtjänstlagen eller utför behandlande åtgärder enligt hälso- och sjukvårdslagen.

Man kan konstatera att även om personligt ombud har tillkommit som en resurs finns det fortfarande behov för psykiatri och socialtjänst att organisera team enligt ACT-modellen (Assertive Community Treatment) med case managers som kan ge service för de personer som ej kommer att få tillgång till personligt ombud. Dessa case managers kan då också ha som uppgift att utveckla samarbetsformer mellan ACT-teamen och de personliga ombuden.

## Summary in English

In 1992 the Psychiatry Commission in Sweden proposed that "long-term and seriously mentally disturbed people" should have the right to a personal representative. A state grant to local councils was approved by the government in 2000 in order to build up and develop personal representative services for people with mental dysfunction. The National Board of Health and Welfare outlined principles for the scheme and the government has charged the Board with leading and co-ordinating the work. The service should be available to people over 18 years of age who have a mental dysfunction with a long-term social handicap and complex needs in respect of care, support and service.

The work reflects the roles of "broker or co-ordinator" and "lawyer" but all decisions are ultimately taken by the mentally dysfunctional and is based on the unique needs of each individual. The personal representatives are not responsible for decisions in accordance with the Social Services Act - neither for treatment nor other aspects of care in required by the Health and Medical Care Act. There is still a need for psychiatric and social welfare services to organise Assertive Community Treatment-teams with case managers to serve those who will not have a personal representative. These case managers can be useful in developing forms of co-operation between ACT-teams and personal representatives.

## Background

In its final report in 1992 the Psychiatry Commission in Sweden proposed that "long-term and seriously mentally disturbed people" should have the right to a personal representative. This proposal was based on studies of "case management" in the USA and the UK. In the government bill following this report, it was pointed out that support to mentally dysfunctional people could be improved if these people received support from personal representatives. In order to achieve a firmer foundation for the organisation and structure of such an agency, it was decided to launch three-year pilot projects in 10 districts. The 10 projects involved 250 mentally dysfunctional people and 32 personal representatives. The National Board of Health and Welfare had the task of follow-up and evaluation. A basic summary of the Board's evaluation revealed that the most common work of representatives was related to advice/support and fact-finding. It also showed clear positive changes in the functional ability and care needs of mentally dysfunctional persons (reduced need for institutional and non-institutional psychiatric care) after 18 months. Moreover, the people involved stated that the projects had positive benefits and considerably more of those taking part in the projects received assistance according to the LSS (Special Support and Service Act) compared to other mentally dysfunctional people. They also concluded that the successful operation of personal representative services was possible in various models of organisation. The pilot projects have shown that a "free-standing" role enhanced the successful work by the personal representatives.

An Information Sheet about personal representatives was published in 2000. In this the National Board of Health and Welfare outlined principles pertaining to personal representatives, the target group, organisation, work assignments etc. The following is a short description based on this information.

#### State Grant for National Development

A state grant to local councils was approved in 2000 in order to build up and develop personal representative services for people with mental dysfunction. The budget for this was SEK 60million for 2001 and SEK 90million for 2002 and thereafter. The grant makes it possible to employ 300 personal representatives.

The National Board of Health and Welfare has been charged by the government to lead and co-ordinate the work. This includes defining the tasks of personal representatives and setting criteria for those to be served. The Board has the responsibility for national supervision, follow-up, support and evaluation of the service as well as encouraging further development. The Board also has the responsibility for developing training and skills development programmes for representatives.

#### Local Councils - Responsible Entities

The Government decision means that personal representative services shall be based on local councils as the responsible entities. Local councils are responsible for ensuring that funding for such services is used as prescribed by the National Board of Health and Welfare with the support of the Drafting Committee.

Local councils are entitled to contract out service operations to other organisations - voluntary or professional. They remain responsible for services and must give the County Administrative Board and the National Board of Health and Welfare an account of how funds are used and how services have developed.

#### Target Group Criteria

The Psychiatry Commission stated that the group of long-term and seriously mentally disturbed people totalled about 45 000. Personal representative services are not designed to be used by all people in this group. The Government decision on state funding is based on the assumption that between 10 and 20 per cent of these may need qualified personal support. Thus 4500-9000 people are targeted.

Personal representative services should be available to people above 18 years of age who have a mental dysfunction which causes extensive and long-term social handicap and which entails considerable hindrance to day-to-day life. People with complex needs who require care, support and contact with social services, primary health care, specialist psychiatry services and other authorities belong to the target group. Personal representative services should potentially also be available to people in care facilities or residential homes, as well as those with both mental dysfunction and addiction.

### Work Assignments

The main tasks for personal representatives are

- " To collaborate with individuals in:
- " identifying and formulating their need for care, support and service.
- " ensuring that these are planned, co-ordinated and carried out.
- " To assist or represent individuals in their contact with various authorities etc.
- " To ensure that individuals receive care, support and service in accordance with their own wishes, needs and lawful rights.

The work covers both the roles of broker, co-ordinator and legal adviser. These are described in the pilot project evaluation as two essential tasks for personal representatives. They are not responsible for decisions in accordance with the Social Services Act nor for treatment or other care under the Health and Medical Care Act.

### Personal Representative and Legislation

The Government's decision involves no legal regulation of personal representative services. Communities have the right to choose if they want to establish an organisation for personal representatives or not. The individuals possess no legal right to a personal representative and cannot appeal to an administrative court on denial of such services. Local councils do, however, have the responsibility, in accordance with the Social Services Act, to seek out mentally dysfunctional people, outline needs and offer services in collaboration with other authorities.

### Attitudes and Principles

The role and work of personal representatives differ in several ways from those of other professionals and are based on distinct principles and attitudes. For instance, all decisions are taken by the mentally dysfunctional and the work is based on the unique needs of each individual. A close long term relationship are cornerstones in the effort to achieve positive results. Work should take place in the natural environment of the mentally dysfunctional, e.g. via house calls.

### Recruitment of Personal Representatives

Crucial to the success of personal representative services is the availability of suitable, competent and interested candidates for the jobs. They need a knowledge of mental dysfunction, a thorough

knowledge of the support, care and services available to individuals in society with mental dysfunction and they need to be well oriented with regard to social, health and medical care legislation.

Experience has shown that personal suitability for and interest in working with the target group should weigh heavily in the recruitment of personal representatives. The majority of those already engaged have long experience of working with the target group, primarily from within psychiatric services but also from social services and, in some cases, social insurance offices and job centres. Some also have experience of mental dysfunction themselves or have a relative with a mental illness.

#### Authors Conclusion

It seems clear that the personal representatives in Sweden will work as brokers, co-ordinators and advocates for their clients. The role is different to the case management-role in the evidence-based Assertive Community Treatment model. Nevertheless there is still a need for psychiatric and social welfare services to organise Assertive Community Treatment Teams with case managers to serve those who will not have a personal representative. These case managers can be useful in fostering co-operation between ACT-teams and personal representatives.

#### References

National Board of Health and Welfare, Information Sheet no 14/00