

A New Profession is Born

– Personligt ombud, PO

ISBN 978-91-85999-64-4
Artikelnr 2008-126-22
Omslag Socialstyrelsen, Fhebe Hjälms
Sättning Edita, Västra Aros
Tryck Edita, Västra Aros, Västerås, november 2008

Foreword

The Psychiatric Care Reform was initiated in 1995 to improve the living conditions of those with psychiatric disabilities, particularly their participation in the community and their care and social support. The preamble to the Psychiatry Bill noted that this support could be considerably improved using patient advocates (personliga ombud, PO) with clearly defined responsibility for drawing attention to the needs of the individual and coordination of help.

In May 2000, the Government decided to earmark funds for municipalities so that they could start permanent PO systems. Since then, the National Board of Health and Welfare has had a Government assignment to work together with County Administrative Boards to coordinate this work among the various authorities and stakeholders. The system is followed up and evaluated on an ongoing basis. In 2005, a report was submitted to the Government, which pointed to positive trends as a result of the work of POs – the scheme is profitable in socioeconomic terms, clients consume less care, their psychosocial situation has improved and their position has been strengthened.

There is great interest inside and outside Sweden in this system and in the new function – Personligt ombud (PO). This short pamphlet summarises the work and the lessons learned from this part of the above mentioned reform.

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Stockholm, September 2008

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A new profession is born

In Sweden, big psychiatric hospitals were still being built and old ones renovated as late as the early 1970s. A few years previously, the regional health organisations (county councils), had taken over responsibility for these hospitals from central government; at the same time, they were in the process of building new clinics within their somatic health care organization. The care of people with serious psychiatric disabilities was largely institutionalised.

Social policy in Sweden and many other western countries subsequently underwent a shift away from big institutions towards community-based care and support better adapted to the individual.

In the early 1990s, a Swedish government commission of inquiry known as the Psychiatry Commission was able to show that people with psychiatric disabilities were not receiving the same share of community resources as citizens in general, that they had the poorest living conditions of all disabled groups, and that there were shortcomings in how individuals were treated and in the coordination of care, assistance and support. The commission proposed that a municipality's responsibility for all its inhabitants, whether with psychiatric or physical disabilities, should be more clearly expressed in the Social Services Act.

It soon became clear that many municipalities lacked the skills to adequately meet the needs of people with psychiatric disabilities. Central government therefore channelled funding over a three-year period to stimulate the development of the social and psychiatric services. This work focused mainly on housing, employment and rehabilitation.

Pilot projects involving a person with a kind of case manager functions – known in Sweden as *personligt ombud (PO)* – were

also initiated at ten places around the country. These projects aimed to provide support of a professional nature to help individuals with psychiatric disabilities get better access to community-based assistance and support available to vulnerable groups.

An evaluation of the PO pilot activities carried out by the National Board of Health and Welfare (a government body answering to the Ministry for Social Affairs) pointed to a number of beneficial effects. Clients with POs were hospitalised less, had a more stable housing situation, and were granted more of the help to which they were entitled under the Act concerning Support and Service to Persons with Certain Functional Impairments (LSS).

In May 2000, therefore, the government tasked the National Board of Health and Welfare and Sweden's regional County Administrative Boards with the coordination of the nationwide buildup and development of permanent PO activities. A preparation group was appointed consisting of representatives of the Swedish Association of Local Authorities and Regions (SALAR), the Swedish National Association for Social and Mental Health, the Swedish Schizophrenia Fellowship, the Labour Market Board and the National Social Insurance Agency.

The task of the preparation group was to establish criteria for which individuals were entitled to help from POs, what the tasks of a PO would be and what principles would apply to the distribution of government funding. This group was later converted into a reference group to monitor the buildup of the activities.

Models from other countries

The Swedish PO system is based on models found in the USA and the UK, where such people are known as case managers. The professional role has existed in the USA since the 1950s, and in the UK for a couple of decades. The overall job of a case manager is to tailor assistance and support to the needs of the client, to help the client cope with the disability. How this happens varies with the case manager's role. The British and American models share a number of features, but do differ markedly in some respects.

In the 'broker model', the manager has an assisting function with respect to the client; together, they plan the services on the basis of the client's choices.

The 'entrepreneurial model', introduced in the UK during local authority reform in the early 1990s, has a slightly different design. Here, the case manager is not only responsible for the budget, but also for investigating the client's needs, planning care, and coordinating and following up contacts with care providers. In such a model, the case manager does not actually have to meet the clients, so a case manager can have a lot of clients – up to 50 in some cases.

In the 'clinical model', the case manager is part of a professional team, and has the overall task of coordinating action. This might involve action undertaken by the social services, or employment, housing, etc., as well as treatment.

Another model is Assertive Community Treatment (ACT), which provides care and support via a community-based programme of treatment and resources. An interdisciplinary team is responsible for the client, and each case manager helps about ten people at the same time.

Another orientation is that of the ‘resource model’. In this model, the work proceeds from the client’s own choices and resources, instead of disease symptoms and problems, and the emphasis is on a good, functioning relationship between the client and the case manager. The model is supportive, with the case manager functioning as the client’s advocate.

What all of these models have in common is the coordinating function, something which also applies to the Swedish PO model. One of the most important functions of a PO is to help clients take control of their own situation; this is known as ‘empowerment’. Another important function is to make demands on the public authorities that are responsible for people with serious psychiatric disabilities, to ensure that they are receiving the help and service to which they are entitled. The POs thus have the role of ‘care demander’.

Another feature that differs from some case manager models is that Swedish POs have no medical responsibility, or responsibility for treatment. Nor do POs make any decisions in the capacity of an authority; *they work to represent the client*.

Who gets a PO?

POs are available to individuals aged over 18 and who, because of their psychiatric disability, have a substantial and long-term social disability that causes them major problems in their daily lives. This is the definition of the target group. Additionally, such persons must have complex need of care, support and service, which means that they are in contact with the social services, primary health care services and/or specialist psychiatry services, or with other public agencies. Others may be people who, in addition to their psychiatric disability, may have a substance abuse problem and/or be homeless.

Each year, about 6–7,000 clients are helped by just over 300 POs distributed over more than 100 organised activities. POs have an average of about 15 clients a year, sometimes up to 25.

There are various ways to establish contact with a PO. It is common for the individual to establish contact, or for the social services or psychiatric services to do so, or that it takes place through a user organisation. There is no formal referral procedure, which means that getting a PO is a fairly straightforward matter.

Cases are however assessed on an individual basis, and it may be hard to get a PO if there are waiting lists. In some parts of the country, young people with a psychiatric disability are given priority; in others, priority is given to those with children. Any priorities are an issue for the PO management body (see below for more about the role of this body).

The surrounding framework

The task of a PO – to make demands on the community to enable the individual to access available rights and resources – is consistent with a long tradition in Swedish disability policy: that of the citizen perspective as a basis for policy. As citizens, we have certain rights. People with disabilities are to be given support and help to provide them with living conditions equal to those of others, so that they can integrate into the community. This perspective includes the view that we should all have power and influence over our everyday lives. Power and control over one's own life is an important determinant in recovery from psychiatric illness.

The importance of the management body

The framework in which the PO works may vary: usually, one municipality functions as the principal and has operative responsibility. In some places however a number of municipalities have merged their organisations, while in others the activity is a county-wide organisation. It may also be operated by foundations, voluntary associations, care associations or other coordinating bodies. The key aspect of the activity is that the public framework around the client should be as close to the client as possible.

Part of the cost of the PO's salary is met by central government funding, with the rest of the salary and other additional costs such as premises, cars, etc., being met by the municipalities involved. County councils co-fund about ten per cent of the activities.

Each PO activity is attached to a management body. It is best if the public agency representatives in the management group have a mandate to make overarching decisions. As well as municipal and county council representatives, the management group should

include representatives from the regional employment board, the Social Insurance Agency, and user associations and voluntary groups.

It is important that the strategic role and task of the management body has the support of all those involved, and that costs are shared among the public agencies. The management body can play a key role, since it is part of the PO's job to call attention to shortcomings in the health and social care systems.

Independent role

POs, then, are to be 'independent' of their principals in terms of organisation, and should preferably not share premises with them. This means that although POs are usually formally employed by the municipality, the activity should be kept separate from the municipality's social services. This independence means that POs are better placed to make demands on public agencies. Since the work of the POs is not limited by the framework governing other professional groups with which the client comes into contact, the PO can more easily work across sectoral borders, thus giving the PO a role somewhat reminiscent of that of a municipal housing support officer or a contact person in the psychiatric services, at the same time as the PO's tasks differ in all important respects from those of these professional groups. This way of working makes it easier to accept different methods, from a medical as well as a more empowerment-focused perspective (see also the Empowerment section below).

This independent role also makes it easier to achieve more unconventional solutions, and – experience shows – to establish trusting relationships with clients. Many clients also feel that their contacts with POs are warmer and more personal than their earlier contacts with those in positions of authority.

This also enables the PO to stand shoulder to shoulder with the client if the client's interests should run counter to the opinions of other professionals. Consider the following example:

After a stay in hospital, a client wanted to live in a flat of his own. Since this was the client's wish, he was supported by the PO, while many other professionals involved with the client advised against it, saying that it would not work out. This in fact turned out to be the case: the client eventually moved into housing with special support and was very happy there. Professionals in the social services and psychiatric services thought that this was an unnecessary failure, while the PO's view was that the reason why the client was so happy in the special housing was that he had been given the chance to live in his own flat.

Working as a PO

Working as a PO means taking the needs of the client as a starting point and then working towards a solution involving the care providers, the Social Insurance Agency and other actors involved with the client. Coordination of actions is not the only thing to be achieved; interests, views and values must also be woven together. Since many clients have a complex array of problems, it is important that there is a common value base regarding psychiatric disabilities and human dignity, how rehabilitation should be designed and what best promotes recovery.

Even though these values may be identical, work methods can still differ; this may be due to relationships with the public systems surrounding the client. Differences in methods may also be due to the location of the activity in a rural or urban area: big cities often have better access to skills and centres of knowledge, and distances are shorter; but on the other hand, the work might be more complicated, subject to change and more impersonal than in rural areas.

The disadvantages of working in rural areas are circumvented by cooperation across municipal borders. This is in fact the case in over half of all activities. It enables municipalities to share costs, and POs to be part of a bigger team, allowing them to develop a variety of cutting-edge skills. It is also easier to arrange training and supervision for a team.

Two or three POs usually work together. Working in a team helps the work proceed more smoothly, for a number of reasons: being a PO can be stressful work, and some of the pressure can be relieved by swapping experiences with colleagues. It may also be easier to make people aware of a more extensive activity, and the fact that there are a number of POs means that there is a bigger

chance that the client can choose a female or male PO, something which many find important.

Working for the client

The Psychiatry Commission expressed an important principle, which was that care, support and service are all to be based on the client's needs. The task of the PO, then, is to help the client express these needs. A condition for this is that the PO and the client have a good relationship and that they trust each other. It is therefore important, when a PO meets a new client, to try to create a confidence-building introductory phase.

Some clients, however, are hesitant about the PO activity, sometimes because they are not convinced that it really is possible to get help on these terms. They might also be put off if a PO slips back into a previous professional role. The challenge is to try to find a role that balances between that of professional therapist and that of friend or attentive listener.

What values, then, must permeate the actual work with the client? Respect, sensitivity, a holistic view, the client in control, a two-way street, a horizontal relationship, focus on opportunities and health, a rehabilitating perspective, support and encouragement are expressions used by active POs. If these words are to mean anything, it is best to describe them using real cases and situations, since this is when the values become clearest.

It is possible, then, to build on the everyday work and basic ethical principles to create a common ideological framework for the work. The important thing to remember is that views and values in the work are not a private matter; they are part of the professional role.

The points of departure of the work can be expressed thus:

- The client's experienced needs and wishes are in focus, not the diagnosis and the treatment;
- The work is based on the client's health and his/her potential, rather than on symptoms, problems and limitations;

- The client chooses the PO, not the other way round;
- The client, and not the PO, sets the agenda and controls the process.

Mapping needs

The next step might be to deal with what the client says that he or she needs help with. After many years in the hands of the care apparatus, it may be difficult for an individual to express their own will. This is because as a patient, the individual felt that nothing they said mattered or that nobody listened. As one woman expresses it:

The biggest problem, as I see it, is that nobody listens to me. I have a feeling that what I have to say, about my life, about my problems, isn't worth anything. That everybody else knows better than I do about how I am and how I function. I'm not important, my experiences don't matter. Because I am hypersensitive about this, I seem to get the feeling confirmed all the time through lots of different occurrences. Now that I have a PO, I feel that I have someone who listens to me, who backs me up.

Different individuals need different amounts of time to express their own will. When this happens, the next step might be to try to map needs and establish a structure and overview of what the client needs to change in his/her life situation. This, of course, varies very much with the individual.

A good tool is the Camberwell Assessment of Need (CAN) model. This is based on needs, not diagnoses, and provides a good picture of the client's situation and what care providers and authorities the person is in touch with. It also means that important things are not forgotten, and can be helpful when moving into sensitive areas such as sexuality.

It is of course possible for POs to create their own written checklists or interview sheets. As usual, it is not the form which is important, but the content. The challenge is to try to achieve change in the client's situation without resorting to traditional treatment.

Some areas that clients often appear to get help with are putting their financial affairs in order, having someone to talk to, and in their contacts with authorities.

The reason a lot of people find it difficult to deal with different authorities is that they do not always know where to turn, and also feel at a disadvantage, which makes it difficult for them to speak for themselves: they feel powerless. One person described their feelings like this:

Nothing feels clear. It feels as if I am just floating around, and don't know anything. They're the ones in the know; they are the ones with the information about what is going to happen.

It is therefore important to strengthen the individual so that they gain power over decisions and actions in their lives. Power and control over one's own life is an important condition for recovery.

Joint action plan

After the process in which needs are mapped, the PO and client together draw up an *action plan* in which it is decided what is to be done, who will ensure that it is done, and when. This can most easily be illustrated using a checklist with a time axis. An important task in the action plan might, for the PO, be to ensure that the work of different authorities is coordinated so that it happens in the right order and at the right time. At such times, the PO takes on the role of broker. Coordination of this type must take place at a meeting involving all those who have contact with the client. After this, it will be the task of the PO to act in the role of lobbyist, urging the various principals on so that the client receives the support, help and care which he or she needs and wants.

A good habit is to subsequently sit down with the client – and sometimes also with colleagues – and draw up some questions for evaluation:

- What did the client want at the outset, what problems did we want to solve, what objectives did we want to achieve?

- What happened, and how did this differ from what we wanted to achieve?
- What is the reason for this difference? Had we misjudged the situation, did something unexpected happen, what did others do that influenced events?
- What conclusions should we draw, what lessons can we learn, and what should we avoid doing in the future?
- How will we act next time we are in a similar situation?

Since the work as a PO is quite new and little known, it is particularly important that POs themselves evaluate what they do, and continually and systematically reflect on this type of question.

Personal and private

Since POs work a lot in the client's home, the question is often asked about how close a relationship may be. In other words, how close can a working relationship be without becoming too personal?

A client decides how much of himself or herself to reveal, and a PO must do the same. There is no established formula for this; it varies widely among POs and with different clients, and changes as the client and PO get to know each other.

Supervision is a good way to stay focused on a professional approach in which the PO learns where to draw the line between being personal without being too private. Group supervision should not take place together with other professional groups, since the work of a PO, for reasons described above, is different, thanks to their independent position, the transsectoral nature of their work and the fact that they make demands on other authorities. Supervision can also be a way to develop the professional role.

A PO often works alone, which means that they have to make a lot of decisions. This is another reason to have supervision. Additionally, working so close to clients can mean that POs learn about situations that can lead to ethical dilemmas. As one PO put

it: ‘The biggest difficulty for me is that I know what is going on in the family – I can’t just shut the door behind me and forget it.’

What this PO found out from the client involved the client’s children, and it was something that nobody else knew about. Since the PO judged that the children were suffering, it was difficult to work solely on the client’s behalf. *The needs of the children took priority.* A PO, like all other public servants, is obliged under Chapter 14 of the Social Services Act to make a report if they know that a child is suffering.

It is important, in situations like this, to have an action plan. This can be drawn up locally in cooperation with the social welfare officer who works to support children and families through the social services.

Ending a client contact

It can be difficult for a PO to end a long-term and close relationship with a client and let someone else take over. Many clients seem to feel the same way. Some also say that they do not wish to be transferred to other support and help, and that they do not have the energy to tell their life story to yet another person. They also say that they want to be helped by fewer people and in more long-term relationships.

It is crucial to make clear right from the start that the job of the PO is to help *build a network* that can take over when the PO leaves, or that an activity is in place which has the type of continuity, flexibility and quality that the client wants. Studies show that if this is in place then the transfer goes well.

A social network around the client also makes recovery, and integration into the community, easier, as well as boosting the chances of an independent life.

What POs need to know

The varying educational backgrounds and work experience of POs means that the need of professional development training varies. Employers looking for POs have usually advertised for personal suitability (something that the clients themselves emphasise), and experience of and skills in dealing with people with psychiatric disabilities. A lot of POs, through previous jobs, have good skills and professional psychiatry experience, with experience of medicine or nursing. They therefore usually know how the disabilities manifest themselves and how they impact on an individual's abilities. They may, on the other hand, need to learn more about the content of social work and learn to develop analysis tools for that type of problem.

Another area in which more training is needed is in legislation and the legal rights that clients have, since the tasks of the POs involve safeguarding these very rights on the assignment of the client. There are also examples, in the stories told by clients, of professionals who overlook the rights of individuals in their professional work, or commit formal errors in their decisions as public authorities. That is why a PO needs to be knowledgeable about social and administrative legislation. This knowledge is also important in coordinated cases so that they can distinguish what laws govern the responsibilities of different principals.

A further field in which more training may be needed is in how to lead network meetings. Interviews with clients reveal how important family members were, not least when no other support was available. For many individuals, family members represent basic security, and since psychiatric care was de-institutionalised they have taken on a key supportive and caring role. So, family members are a key resource in the social network. Since a PO may

be the one convening a network meeting, and the one chairing it, it is also important to boost skills in chairing such meetings.

In the same way, stakeholder organisations and their knowledge of what it means to have a psychiatric disability, or what it means to be a close relative of a disabled person, are an important source of knowledge and understanding. Many POs also work closely with family members and clients through study groups that they attend together, or via the management bodies, which include representatives of clients and their families. Cooperation like this makes it possible to reflect on the role of the PO in the light of what is already known about the situations of clients and relatives. Such close cooperation can also promote empowerment-oriented work methods. If a PO does not enjoy the confidence of family and client organisations, it may be difficult to gain the confidence of a client.

How important is the work of POs?

A report from one Swedish county shows that when people with psychiatric disabilities first came into contact with POs, about 25 per cent were the object of help that did not agree with their needs, 15 per cent had inadequate help and 40 per cent were in receipt of uncoordinated help. As many as 15 per cent were not receiving any help at all and 5 per cent felt that nobody wanted to, or could, help.

During the pilot stage of the activities, as described above, it was already clear that the work of the POs generated benefits. A few years later, after the activity became a permanent fixture, it was found that not only were the benefits apparently permanent, but that they had also been reinforced. There was clear growth, for example, in the number of clients with meaningful occupations, social contacts had more than doubled, symptoms of psychiatric illness were fewer, and care, support and help were more consistent with what people wanted.

Since the help provided thus better corresponds to the clients' needs, and is coordinated, it benefits the recovery process and boosts the individual's quality of life. The PO system thus bears out the intentions of Swedish psychiatry reform, namely that people with psychiatric disabilities should be given the opportunity to become normalised and assimilated into the community.

A study carried out in one county showed that the PO system can bring considerable macroeconomic benefit; once a person with a psychiatric disability has established contact with a PO, a radical shift takes place away from passive and expensive help such as psychiatric care and income support towards more active help such as rehabilitation, employment, psychotherapy, a contact person, assistance, home help services and so on.

Calculations show that the work of POs is worth about SEK 40,000 per client. Over the five years that follow a client's having obtained a PO, costs to society fall by about SEK 700,000. This represents savings equivalent to 17 times the costs.

Point out shortcomings in the system

As we have seen, the job of PO is a many-faceted one. Apart from supporting the client, a PO may in some cases need to represent the client (the PO should, in such cases, obtain a power of attorney from the client).

Another task might be to find unconventional solutions to a problem. A further task is to convene network meetings involving those around the client, to find out what public agency is to do what, and also to describe obvious shortcomings discovered during cooperation to help and support clients. Shortcomings might concern inappropriate treatment by staff at the municipality or county council, employment office or social insurance office, that clients have a low standard of living that makes recovery more difficult, that it is hard to get hold of people who are important to the client, an inability by principals to think flexibly, pointing out how laws and statutes act counter to each other, and that there are coordination and collaboration problems between authorities.

Coordination problems may occur when individuals have a substance abuse problem in addition to their psychiatric illness. Since problems related to the substance abuse fall under the remit of the social services, and psychiatric disabilities that of the county council, there is a clear risk that the individual will end up in a no man's land that nobody is responsible for. Such problems can be avoided, however, if help and support are better coordinated.

A more detailed description of how shortcomings in coordination can occur is that of a young woman who turned to her PO because she was refused income support.

She had applied for income support from the social services, but their condition was that she must first register as a jobseeker with the employment centre. At the employment centre however, they thought that she could not cope with a half-time job, which is the condition for jobseeker status. Along with her PO, the woman then went to see a doctor who was to assess whether she was sufficiently ill to be put on sick leave. She was not assessed to be so ill. This meant that the woman could not get any help anywhere. Her PO then arranged a network meeting with those involved, to reach a solution.

By convening the network meeting, the PO took on the role of broker. In describing the problems for the management body, the PO was attempting to remove obstacles to the client's chances of receiving help from the community. An important area of work for a PO is, then, to work in the community, since it is not automatically the case that an individual's situation will change if structural problems in the community, and involving people with psychiatric disabilities, are allowed to persist. When such shortcomings are discovered, it is important that the management body gets to grips with them.

'It's just like we POs say: we can only do certain things, and that's not what this reform or this activity is about. You can give huge amounts of help to individuals, but the whole idea is that these clients should improve their situation as a group; that they should have their status raised somehow,' says one PO.

Another reason why it might be important to point out flaws in the 'system' to the management group is that it can be a factor in the quality assurance work of the principals. As one member of a management body put it:

'It's about quality issues, and for me, finding out about something that isn't working is a quality issue, because we can do something about it.'

The prerequisite for a PO's being able to turn to the management body and discuss problems and dilemmas is that the representatives are not, in their daily work, directly responsible for personal sup-

port to the clients of the POs, or are in any other way operatively active in social psychiatric work involving the clients.

Empowerment

A PO works on the assignment of the client in a social context. By not 'seeing' the client's disease and weakness, but rather his or her strengths, the PO helps create opportunities for the client to have greater influence over his or her social situation, which boosts the chances of recovery and a more independent life. In this context, POs function as tools in a process in which the client develops greater self-reliance, which means the client gaining more power and control over his or her life. When an individual does this, it highlights things that perhaps were previously regarded as shortcomings and individual problems, frequently in terms of disease.

A PO who supports the wishes and requests of a person with psychiatric disabilities thus empowers that person.

The term 'empowerment' has its roots in advocacy groups and describes an ambition to improve the situation of a group of people in society and in the care and support that they receive.

The psychological dimension is all about greater self-esteem. A study of the work of POs shows that there is a link between a greater degree of experienced empowerment and a strengthened social network around the client.

There is also a clear link between empowerment and stigmatisation, meaning negative attitudes and values regarding a specific group in the community. If people feel disrespected, they are prevented from participating in the community. Measures that boost individual empowerment do not just affect how people experience attitudes and values in the community, but also how they are able to deal with them.

From this, we can also draw the conclusion that a reduction in negative attitudes and values in the community regarding people with psychiatric disabilities leads to greater empowerment.