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The Personal Ombudsman System in Sweden

Presentation at

1er Seminario Internacional sobre Discapacidad, Salud Mental y Cuidado
Facultad de Medicina, Universidad de Chile, Santiago de Chile 28 March 2015

I will tell you a little about our service PO-Skåne¹, which we started in 1995. It has become well known all over the world, especially in connection with the UN Convention on the Rights for Persons with Disabilities (CRPD). Our service is for example presented in “The World Report on Disability”, published by the World Health Organization and the World Bank in 2011².

Article 12 of the CRPD clearly states that all forms of guardianship are against the Convention, and should be abolished. For persons who have difficulties to express or communicate their decisions and wishes, the state should take appropriate measures to provide the support these persons may require in exercising their legal capacity. This means that decision-making shouldn't be taken away from them and handed over to another person (such as a guardian), but remain with the disabled persons themselves, although they might need some help to express and communicate their decisions. ‘Substituted decision-making’ should be abolished, and replaced by ‘supported decision-making’.

The Personal Ombudsman is a concrete example of ‘supported decision-making’. There is a great interest in our service now, when many countries are considering the option of abolishing their old guardianship systems, and replace it with some form of ‘supported decision-making’. In January 2006 I presented PO-Skåne in the UN Headquarters in New York. Since then I have presented it at conferences in 14 countries – in some of them several times.

But our service started 10 years before the UN Convention was adopted, in another context, namely the experience of us who are users and survivors of psychiatry, and our ideas of the support we think we might need in certain situations.

The Swedish system with Personal Ombudsmen came out of the Swedish psychiatric reform in 1995. The aim of this reform was to rectify some of the problems that had arisen when the old mental hospitals were closed down during the preceding 25 years.

¹ <http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>

² The full report is available at http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf p. 138

Today many Swedes think that the system with locking huge numbers of people up in mental hospitals is a very old system, but it's not. In the year 1850 there were only 800 psychiatric patients in mental hospitals in Sweden. 50 years later- in the year 1900 - the number had risen a little to 1000 patients. In the 20's the total number of psychiatric patients in mental hospitals in Sweden was 4000. Then the number grew rapidly, and reached its peak in 1967, when there were 37.000 psychiatric patients in mental hospitals in Sweden.

The politicians understood then that there was something fundamentally wrong with this asylum system. The mental hospitals were never meant to become depots for huge numbers of persons with mental health problems. They were meant as a place for persons to stay for a short period for treatment, before they were sent back to society. But instead the mental hospitals became confinements for huge numbers of persons.

The politicians understood that something had to be done. Those big institutions were cruel, inhuman places. Instead of helping persons with their mental health problems, those institutions just created lifelong confinements and permanent disabilities.

In the 70's the process of closing the mental hospitals started in Sweden. But the social services in the municipalities weren't prepared for this. It took some years before the municipalities started to build new services for persons with mental health problems, now living in the community instead of isolated in asylums.

In the 90's the support systems for persons with mental hospitals were quite well developed in the municipalities, but still they didn't work very well. One problem was that the responsibilities of the health authorities and the social services weren't divided in a clear way. This meant that the two agencies sometimes did the same thing – for example running group homes – and thus overlapping each other. But it also often created a wide gap between those two agencies, where none of them took any responsibility at all, which meant that persons with mental health problems were left without support. The psychiatric reform of 1995 was meant to rectify these problems by clarifying the responsibilities.

The committee preparing the reform had noticed that something essential was missing concerning the support persons with psychiatric problems received from society. The municipalities had developed quite good programmes for housing, rehabilitation, supported employment and so on, but nevertheless the support for persons with severe psychosocial disabilities didn't work very well. The parliamentary committee came up with the idea of something completely new, which they called 'personal ombudsman' (shortened PO). But they had only a very vague idea what this should be. They thought that there should be someone, who could help persons with severe psychosocial disabilities to get what they needed and wanted, but not much more.

In order to develop this new idea, the parliament decided to finance ten projects with personal ombudsmen in the course of three years. They discussed a lot about who should be the

principals for those new services. Some thought it should be the government, but others that the service must be run by independent organizations, to avoid the conflict of interest. The personal ombudsmen were compared with lawyers, who must be independent to be able to defend their clients. Because of these conflicting opinions, the parliament decided that different models for the PO-services, with different principals running them, should be tried during the project period 1995-1998.

When I heard about this, I thought this was a good chance for us to develop a PO-model of our own. I wrote an application for project funding, and our project was one of the ten projects selected, although the National Health Board had received hundreds of applications. Our project was one of two that had a service user organization as its principal. All the other projects were run by local governments.

The project period 1995-1998, which was researched thoroughly by two researchers appointed by the National Health Board, showed extremely good results - both in qualitative and quantitative outcomes. Actually this project was the only element of the psychiatric reform of 1995 that could show any success. This led to a decision by the Swedish parliament in 2000 to support the development of personal ombudsmen in the whole country – still with different principals running the services, as the parliament still couldn't decide which model was the best.

Now – 15 years later – we have in Sweden 310 POs that provide supported decision-making for more than 6.000 individuals. 245 municipalities – which is 84 % of all municipalities in Sweden – include POs in their social service system. In 2013 we got a new regulation that includes the PO system in the regular welfare system.

The PO system is actually also saving huge sums of money for the government. Studies show that PO operations reduce costs by approximately 80,000 Euro per assisted person over a five-year period. For every 1 Euro the government spend on the PO system they gain 17 Euro. So it is also a good business.

The municipalities can choose to run the PO service themselves, or contract some NGO, who run it for them. We think it's important that the PO service is independent from the government – to avoid conflicts of interest, and to gain trust from the persons who need the service most.

Our service PO-Skåne is an NGO who operates on contracts with 15 municipalities in the province of Skåne. This makes our service much bigger than the local ones that are run by only one municipality itself.

Now I will tell you a little bit about how the PO's work in practice. As the time is short I will use bullet points to address the main features of the service:

- A PO is a professional, highly skilled person, who works to 100 % on the commission of his client only. The PO is in no alliance with psychiatry or the social services or any other authority, and not with the client's relatives or any other person in his surroundings.

- The PO does only what his client wants him to do. As it can take a long time – sometimes several months – before the client knows and dares to tell what kind of help he wants, the PO has to wait, even though a lot of things are chaotic and in a mess.

- This also means that the PO has to develop a long-time engagement for his clients, usually for several years. This is a necessary condition for developing a trustful relation and for coming into more essential matters.

In our service with personal ombudsmen the most important thing has been to develop ways to work which are adjusted to this special group of persons with mental health problems of the most difficult kind. In other projects it is usually the clients who have to adjust themselves to a bureaucratic system, but we work in the opposite way. The PO's have to be very flexible, creative and unconventional in finding ways to work with this group.

I will briefly introduce some pre-conditions which we think are necessary if you really want to reach these persons and practise supported decision-making with them:

- The PO doesn't work Monday-Friday at office hours only. The week has 7 days and each day 24 hours – and the PO must be prepared to work at all these various hours, because their clients' problems are not concentrated to office hours and some clients are more easy to contact in evenings and weekends. The PO has to work 40 hours a week but makes up a flexible working-scheme every week according to the wishes of their clients.

- The PO hasn't got any office, because "office is power". The PO works from his own home with the help of telephone and internet – and he meets his clients in their home or at neutral places out in town.

- The PO works primarily according to a relationship-model. As many clients are very suspicious or hostile, or hard to reach because of other reasons, the PO has to go out and find them where they are – and then he has to try to reach them through several steps: 1. Making contact, 2. Developing a communication, 3. Establishing a relation, 4. Starting a dialogue, 5. Getting commissions. Each of these steps can take a long time to realize. Just to get contact can sometimes take several months. It could mean going out and start talking with a homeless psychotic person in a park or talking through the mail drop with someone who lives very barricaded. Not until a relation is established and a dialogue has started can the PO start getting commissions from his client.

- There should be no bureaucratic procedure to get a PO. If a form had to be signed or an admission note been necessary, many psychiatric patients would back out and not get a PO – and it would probably be the persons who need a PO most. To get a PO from PO-Skåne doesn't involve any formal procedure. After a relation is established the PO just ask "Do you want me to be your PO?". If the answer is "Yes" the whole thing is settled.

- The PO should be able to support the client in all kind of matters. The priorities of the client are usually not the same as the priorities of the authorities or the relatives. According to 10 years of experience the clients first priorities are usually not housing or occupation, but existential matters (why should I live? why has my life become a life of a mental patient? have I any hope for a change?), sexuality and problems with relatives. A PO must be able to spend a lot of time talking with their client also about these kind of issues – and not just fix things.

- A PO should be well skilled to be able to argue effectively for the client's rights in front of various authorities or in court. All PO's of PO-Skåne have some kind of academic degree from the university or some similar education. Most of them are trained social workers, but some are lawyers and some have other specialised training.

- The client has the right to be anonymous for the authorities. If he doesn't want his PO to tell anybody that he has a PO this must be respected. PO-Skåne gets money from the community for the service, but there is a paragraph in the contract that says that the PO could deny to tell the name of their clients to the community.

- The PO doesn't keep any records. All papers belong to the client. When their relation is terminated, the PO has either to give all papers to the client or burn them together with the client. No paper and no notes will remain with the PO.

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Videofilms:

Paving the Way to Recovery. A Mental Health Europe Film on the Personal Ombudsman System: <https://www.youtube.com/watch?v=xqma4wK8sC0>

Amnesty International. Supported Decision-Making in Theory and Practice. Ireland's Capacity Bill – Maths Jespersen on Sweden's Personal Ombudsman System as an Example of Supported Decision-Making: <https://www.youtube.com/watch?v=t6scSjDq21I>