

## Maths Jespersen

### PO-Skåne – a concrete example of supported decision-making

Presentation at the OHCHR Symposium on  
the Human Rights of Persons with Psychosocial Disabilities  
Forgotten Europeans Symposium No 5  
at Martin's Brussel EU Hotel 17 October 2014

I will tell you a little about our service PO-Skåne<sup>1</sup>, 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 2011<sup>2</sup>. 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.

It's hard to translate our Swedish word ‘personligt ombud’ into English. The most accurate translation is probably ‘personal agent’, but I usually translate it as ‘personal ombudsman’ to be able to use the same abbreviation in English as in Swedish, namely PO. And ‘personal ombudsman’ has now become the established translation, figuring already in thousands of international texts.

Before I go into details about our PO-service, I will tell you a little about its connection with the UN Convention, as this gives a clear idea of what the Personal Ombudsman is all about.

In January 2006 I presented the PO-Skåne in the UN Headquarters in New York. It was in a so called side event during the lunch break of the Ad Hoc Committee, which was preparing the CRPD. There were usually three or four such side events during the lunch break between the two daily sessions, and they were part of the official programme. Our side event was organized jointly by the World Network of Users and Survivors of Psychiatry (WNUSP)<sup>3</sup>, MindFreedom International<sup>4</sup> and Inclusion International<sup>5</sup>, and was sponsored by the state of Canada. The hall was overcrowded, which meant that many of the UN ambassadors couldn't find a chair, but had to sit on the floor to listen to us 6 speakers.

---

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

<sup>2</sup> The full report is available at [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf) p. 138

<sup>3</sup> <http://www.wnusp.net/>

<sup>4</sup> <http://www.mindfreedom.org/>

<sup>5</sup> <http://www.inclusion-international.org/>

The purpose of our side event was to convince the state delegates of the necessity of making a radical paradigm shift, when coming to Article 12 of the Convention - the Article on 'legal capacity'. Besides arguing from a human rights perspective in a theoretical way, we thought that we also had to present some practical examples of 'supported decision-making', to show that this is possible also for persons with the most severe psychosocial and intellectual disabilities. We had to combat the argument of guardianship "as a last resort" for this very difficult group - by showing through concrete examples, that guardianship and other forms of 'substituted decision-making' aren't necessary.

The responses from the audience were overwhelming. The state delegates were very enthusiastic about our PO-service, although they didn't know whether it was possible to implement something like that in their own countries. I remember especially the head of the Disability Unit at the US Ministry of Justice, who came to me after my presentation and said: "This is very good. But that is Sweden. You have money for that kind of things. I don't think it's possible here in America."

Anyway, our side event had its effect. In the afternoon session the Ad Hoc Committee discussed Article 12, and suddenly the paradigm shift occurred, when the delegates – after a hard discussion – came to the conclusion that 'substituted decision-making' is degrading the personhood of the disabled person, and against the purpose and meaning of the whole Convention, and therefore must be replaced by 'supported decision-making'. Subsequently the text of Article 12 was changed into the final version we now have.

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'.

As personal ombudsman is a concrete example of 'supported decision-making', there is a great interest in this model now, when many countries are considering the option of abolishing their old guardianship systems. And because of this I have presented our service in a range of European cities, like Oslo, Copenhagen, Dublin, Killarney, Brussels, Berlin, Alzey, Vienna, Lisbon, Florence, Ljubljana, Belgrade, Sofia, Budapest, Prague and Riga. Before I go into details about how the PO-service works, I will go back to its very beginning in 1995.

The Swedish system with Personal Ombudsmen came out of the Swedish psychiatric reform in 1995. 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'. 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.

This new idea of personal ombudsmen fitted very well into my own experience and thinking. I have not enough time to tell you about this now, but some of you might already have heard some of my earlier presentations on these subjects in various countries, or read the printed versions of them in English and German books. I'm thinking for example of my alternative model called 'The Jungle Model', which I presented for the first time at the Congress of the World Association for Social Psychiatry (WASP) in Hamburg in 1994, and which is published in the book "Abschied von Babylon". Or our user-run hotel Magnus Stenbock, which I presented in many European cities, and wrote articles about in several international books.

When we started our PO-service in 1995 we only had two PO's, and me as the project manager. 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.

As the PO now had become a permanent service, and with much wider spread than during the project period 1995-1998, we also decided to reorganize our own service. Until then our service with two PO's was run by our regional user organization RSMH-Skåne (the Skåne district of the Swedish National Association for Social and Mental Health), but in 1999 we asked the regional family organization IFS-Skåne (the Skåne district of the Schizophrenia Fellowship) if they would join us. And in the year 2000 we jointly founded the new organization PO-Skåne (Personal Ombudsman in Skåne).

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.

#### References:

- Jespersion, M. (1993), Was hilft mir, wenn ich verrückt werde? In Kempker, K. Lehmann, P. (Hg.), *Statt Psychiatrie*, Peter Lehmann Antipsychiatrieverlag, Berlin (S. 38-40)
- Jespersion, M. (1995), Die Befreiung von der psychiatrischen Diagnostik durch Selbsthilfe. In Bock, T. Buck, D. Gross, J. (Eds.) (1995), *Abschied von Babylon. Verständigung über Grenzen in der Psychiatrie*, Bonn, Psychiatrie Verlag (S. 195-200)
- Jespersion, M. (1997), Magnus Stenbock: A User-run Hotel in Helsingborg. In: L. Boone (Ed.), *20 jaar – ans – years Hand in Hand*, Gent: Hand in Hand (p. 172-177)
- Jespersion, M. (1998) Das Hotel Magnus Stenbock. Ein nutzerkontrolliertes Haus in Helsingborg. In Kempker, K. (Hg.) *Flücht in die Wirklichkeit. Das Berliner Weglaufhaus*, Peter Lehmann Antipsychiatrieverlag, Berlin (S.71-76)
- Jespersion, M. (1998), Zwischen lobotomie und Antidepressiva. In Lehmann, P. (Hg.), *Psychopharmaka absetzen*, Peter Lehmann Antipsychiatrieverlag, Berlin (S. 55-57)
- Jespersion, M. (2002), Between Lobotomy and Antidepressants. In Lehmann, P. (Ed.), *Coming off Psychiatric Drugs*, Peter Lehmann Antipsychiatrieverlag, Berlin/Eugene/Shrewsbury (p. 75-76)
- Jespersion, M. (2002), Contribution in: Dachverband psychosozialer Hilfsvereinigungen (Hg.) (2002) „Der Chef bin ich“ – Vom Versorgungsempfänger zum Auftraggeber. Zur Diskussion um Heime und Nutzerrechte, Bonn.

Jesper son, M. (2003), Das nutzer-kontrollierte Hotel Magnus Stenbock in Helsingborg. In Psychosoziale Umschau, 18. Jg. Nr. 3 (S. 39-40)

Jesper son, M. (2007), Hotel Magnus Stenbock – Ein nutzerkontrolliertes Haus in Helsingborg, Schweden. In Lehmann, P. Stastny P. (Hg.), Statt Psychiatrie 2, Peter Lehmann Antipsychiatrieverlag, Berlin (S. 166-173)

Jesper son, M. (2007), Der Personenbezogene Ombudsman in Skåne. Eine nutzerkontrollierte Dienstleistung mit persönlichen Agenten. In Lehmann, P. Stastny P. (Hg.), Statt Psychiatrie 2, Peter Lehmann Antipsychiatrieverlag, Berlin (S. 311-316)

Lehmann, P. Jesper son M. (2007), Psychiatrie, Käfighaltung und Internet. In Lehmann, P. Stastny P. (Hg.), Statt Psychiatrie 2, Peter Lehmann Antipsychiatrieverlag, Berlin (S. 385-398)

Jesper son, M. (2007), Hotel Magnus Stenbock: A User-controlled House in Helsingborg, Sweden. In Lehmann, P. Stastny P. (Ed.), Alternatives Beyond Psychiatry, Peter Lehmann Antipsychiatrieverlag, Berlin/Eugene/Shrewsbury (p. 161-168)

Jesper son, M. (2007), Personal Ombudsman in Skåne. A User-controlled Service with Personal Agents. In Lehmann, P. Stastny P. (Ed.), Alternatives Beyond Psychiatry, Peter Lehmann Antipsychiatrieverlag, Berlin/Eugene/Shrewsbury (p. 299-304)

Lehmann, P. Jesper son M. (2007), Self-help, Difference in Opinion and User Control in the Age of Internet. In Lehmann, P. Stastny P. (Ed.), Alternatives Beyond Psychiatry, Peter Lehmann Antipsychiatrieverlag, Berlin/Eugene/Shrewsbury (p. 366-380)

Jesper son, M. (2008) Das Hotel Magnus Stenbock in Helsingborg – eine Projektbeschreibung. In Verein LOK – Leben ohne Krankenhaus, Vom Schönen Schein der Integration. Menschen mit Behinderung am Rand der Leistungsgesellschaft, Bibliothek der Provinz, Weitra (S. 225-233)

#### 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 Jesper son on Sweden's Personal Ombudsman System as an Example of Supported Decision-Making: <https://www.youtube.com/watch?v=t6scSjDq21I>