Independent living – also for persons with psychosocial disability?

I will start out to claim the following:

“If you as a person with psycho-social disability do not have equal recognition before the law, all of the other human rights will fail to work.”

And this means that even independent living also are challenged. I will try to come with examples of this from my experience in Denmark.

But first of all I will sketch out where we are now seen from the perspectives of Users/survivors of Psychiatry.

We have in ENUSP been able to follow the development in psychiatry and the deinstitutionalization process:

From the 70s the main theme was: from asylum to the streets

From the 90s: from the streets to community services

From 2001: From community services to the labor market

And now it’s time for: From partial rights to full and equal rights

I will start with an optimistic survey from Copenhagen which shows that in the group of people that currently are monitored to use psychiatric hospitals and community services more than 92 % are living in their own apartment’s, many are married and having a life that are comparable to the general population’s, kids, work etc... the only flaw in this survey as far as we see it are that the survey are not including the homeless.

There are about 10.000 homeless in Denmark and almost 50% percent are considered to have mental health problems.

The last 8 % are living in different community based settings and there are in Copenhagen 4-5 mega institutions with around 180 persons in each. These institutions have been criticized for the last 20 years because of their discount
service with 12-14 m³ rooms, 10 people sharing toilets and bath and high prize pr. square meter - They are called living centers and have status as peoples own homes but in reality they can be seen as cheap psychiatric hospitals in community settings. As a person living there you cannot choose which psychiatrist you want there a psychiatrist service to the centers who are in charge of the medication.

This has led to death of many young people 5 in one year in one place.

In Europe many people are concerned that Romas live expectancies are 11 years shorter than other Europeans – this can be seen as a measure of how oppressed and excluded they are – but people with psychosocial disabilities live expectancies are around 20 years shorter than average. What does this tell us?

It tells us that even if we have come to a point where people are living fairly independent – the chemical control of people with psycho-social disabilities have moved from the institutions and out into the community and into people’s homes.

Community Treatment Orders are being used in many European countries and that means that the privacy of your home is broken – it do not concord with the concept of independent living.

One of my friends said to me when the debate was in Denmark – “One thing I looked forward to when I was committed was to be discharged from the Hospital – but how can you be discharged from your own home?” –

There have been a tendency all along that the chemical control, dampening effect of neuroleptics have followed patients out from the asylums and into their own homes.

In Denmark there are few cases of Community treatment orders because there are a lot of restrictions in using it, it’s different in Norway, Sweden and England as far as I know.

But in Denmark there are another alarming developments. Forensic psychiatry has not changed in spite of the new rights provisioned by the CRPD. That means if you make a criminal offend and are a person with psychosocial disability you cannot go to prison you get a sentence to treatment or a sentence to placement.
The last years there have been an exponential rise in these sentences.

A research have been made on the request of the user movement and the result is that 50% of the rise is due to things happening while people are inside the psychiatric hospitals. What does this tells us- two things – people today do not accept to be stripped of their human rights and if the doctors try to use forced medication, belt fixation or ECT without consent using force – people will stride and try to defend themselves which in turn press the professionals to call the police.

I just have one case right know where a person have got a sentence to treatment – he could only get home if he said yes to extreme heavy depot medication. So he like others are in a dilemma – do he want to come home – sleeping most of the time and with serious side effects or do he bear to be in the hospital- his choice.

Independent Living without the other provision of right to privacy, the sanctity of your home, equal recognition before the law or even right to life – is only an illusion.

Instead of mental health laws there should be an inclusive law on patient rights where disability neutral rules – that would say general rules for all citizens should be.

Advanced directives (psychiatric testaments) should be legally binding so people with psychosocial disabilities in times of non-crisis could decide which treatment they would say yes to in case they came in crisis.

Sentences to treatment and sentences to placement should be replaced with normal disability neutral justice. As a principle all control, punishment and other restrictions should be left to the police and all that have to do with treatment should be based on contact not control, open dialogue instead of silent medical dialogue.

A personal note: If I wanted to have a criminal career – It would not be possible for me to enjoy a prison cell – I would probably get a sentence to treatment or placement on indefinitely time- my sister got a sentence to treatment because she could a wild duck in the village pond and scratched a police car. If she was sentenced by the normal law she would probably have paid a fine. This is in my mind a kind of apartheid.
To sum up:

Even if it is possible on the surface to live independently in the society – the special health laws and psychiatric outreach and control are violating the dignity of people with psychosocial disabilities which leads to direct and indirect oppression life expectancies 20 years shorter, exclusion and discount services.

Our status as citizens with equal rights need to be established ... how do we do it?