Beyond the walls: the transition from hospital to community based care. Deinstitionalisation and International Cooperation in Mental Health.

Erveda Sansi - 2011 April 15th

I thank the organizers of this conference for inviting me to speak. First of all I would like to announce the *European MadPride*, organized by two Belgian mental health users associations, *Till Uilenspiegel* and *Psitoyens* with the support of the *European Network of (ex) - Users and Survivors of Psychiatry (Enusp)*, that will be held during the days around October 2011 the 8th. Accepting others in all their diversity is key to positive and nurturing societies. Such is the basis of the *Mind Freedom* concept, from which *MadPride* events take inspiration, whose aims are: to celebrate our diversity, including our own madness; to celebrate the power of self-determination of the free human spirit; to introduce to a wider public the degree of stigma and social exclusion suffered by people who are deemed mentally ill or psychologically different, including abuses of psychiatry; to support and promote the interests of people who are deemed mentally ill or psychologically different; to acknowledge our sincere desire in wanting a constructive dialogue, even if critical at times, with mental health professionals and policy makers at all levels. There will be joyous and peaceful demonstrations in streets, local joyful and non-violent happenings, outdoor theatre performances, stands, speeches, writings, poetry readings and so on. *Jacques Bonnafé* once said: "It is possible to judge the degree of evolution of a society by the way it treats its mad people".
I am here as a representative of *Enusp*, and although I'm Italian (I'm coming from the Lombardy region), it seems to me that I'm arrived from abroad, in the sense that I found here a reality of the psychiatry completely different from that one I knew. I'm very surprised that despite the facts that here they are operating since many years to realise the de-institutionalization and the overcoming of the asylum ideology, and that the positive results, both in economically and human terms, are before anybody's eyes, this model is only scarcely imitated. In Italy, out of a total of 321 SPDC (Psychiatric Services for Diagnosis and Treatment), there are only about 15 that constitute part of the *Club of open SPDC no-restraint*, that means that they declare publicly not to lock the doors and not to use any means of restraint.
The situation in Italy, with some exceptions, and also in some other realities in Europe, has worsened from the period of questioning psychiatric institution, in the beginning of the sixties. Italy has been at the forefront of the closure of mental hospitals. Not only Franco Basaglia and many professionals, but also a good part of the common people realized that psychiatric hospitals were not places of care. Civil society, then, was sensitive to the issue of smash-down asylum culture, launched by Franco Basaglia. Publications appeared, there was an open debate, workers and students organized themselves, and entered in asylums to see the conditions in which their fellow citizens were locked up. They protested and denounced the deplorable conditions the internees

were forced to live in.
But since several years, we observe a re-institutionalisation process and, at the same time, in some Italian hospital's psychiatric wards happened many deplorable facts, due to the institutionalization and forced restraint.
Some of these facts have become infamous after that committees and relatives have seeked justice, as in the case of the teacher *Franco Mastrogiovanni*, that was debated also on national television channels. *Franco Mastrogiovanni*, after a forced psychiatric treatment in 2009, in circumstances that have been the subject of pending penal proceedings, has been heavily sedated, tied to the bed of *Vallo della Lucania'*s hospital psychiatric ward, and left to die after four days of abandonment. A hidden camera recorded everything; the video is of public domain.
Giuseppe Casu, guilty of having wanted to pursue his peddler job in the village square, died after being hospitalized against his will, bound hands and feet to the bed during seven days, after having been heavily sedated.
A 34 years old Nigerian, *Edhmun Hiden*, was voluntarily hospitalized in a psychiatric ward in *Bologna* in May 2008; the next day he decided to be discharged, because he did not feel cared. At this point he was sedated, tied to the bed and held in place with the help of police; he died soon after, due to a heart attack.
These are just some of the cases that came to the limelight, but many more of them are not known when they happen. As, for example when people that live in loneliness are involved, or people whose relatives have given their consent, or simply when people want to get rid of a person perceived as annoying. Personally, I am constantly getting acknowledged of forced psychiatric treatments, during which treated people suffer heavy damages. Forced treatments are often made on request of relatives, when patients refuse to take any longer the psychiatric medications, or when their behaviour is perceived as annoying. A friend of mine tried to escape, but he was chased and filled with drugs; shortly after he was found dead at the bottom of a ravine. He was 40 years old. Another friend of mine was walking on a path between fields and was stopped by police, because he was known as a "mentally ill" person. Then they called the psychiatrist on duty and told him: "He was walking near the railway and could possibly have in mind to commit suicide"; so they locked him up. I know this person, who often walks in the fields, where, however, it's easy to be located near the railway, because of the constitution of the territory. Another acquaintance of mine died, throwing himself under a train, terrified by the fact that his mother, according to the psychiatrist, would refer to forced psychiatric treatment for him. Another one has suffered of heavy harassment, after having reported his superior's embezzlement, noticed during his duties as a municipal technician. He was subjected to forced psychiatric treatment, kidnapped by police in riot gear. While he was sleeping, his door was smashed down, and he was thrown on the ground face down and handcuffed. He says that at least they could have tried to open the door, which was not locked. Now he is terrified and he even fears the dark; he is forced to take psychiatric drugs. We can not think of de-institutionalization

before we have dismissed the rules that allow forced psychiatric treatment, that allow to hold a person against his will, without him having committed any crime, without the right to an equitable process, based on the alleged dangerousness and only because this person was diagnosed with a mental illness. Legislation of forced psychiatric treatment provides ample scope for arbitrariness and it is in strong contrast to the human rights regulations, that aim at preserving even people with disabilities from inhuman and degrading treatments. For those who commit a crime, it is expected that the judicial authority, within certain specific procedural rules, sanctions or imposes restrictive measures. I constantly deal with people in forced psychiatric treatment, that can no longer find a way out of the psychiatric institution.

Dr. Calchi Novati, a Niguarda's Hospital psychiatrist, was strongly mobbed because she opposed the practice of restraining patients, not only by the straps, but also through the shoulder ("spallaccio") of asylum memory, or with other degrading practices. She preferred to have an open dialogue with her patients, resize or scale down the intake of psychiatric drugs, deal with their existential problems. In a few days *Dr. Calchi Novati* would undergo the third disciplinary proceeding of the Disciplinary Board, and now she is in danger of dismissal, because in 2010, she had complained about her working difficulties with a small circle of friends on facebook. Meanwhile her patients have signed a petition with 500 signatures asking that the doctor would be readmitted into her workplace. Other professionals who disagreed with the practice of restraint in respect of patients in the Niguarda's psychiatric wards - which otherwise is a hospital of excellence - have been mobbed or transferred. In December 2010, a series of complaints was presented by relatives of people who died or have suffered as a result of restraint. Following these complaints, since 2006, at Milano Niguarda Hospital's psychiatric wards *Grossoni I, II and III,* 13 people died, mainly due to the practices of restraint and abuse of psychiatric drugs. It would be important to spread the awareness that the restraint is an anti-therapeutic act, that makes cures more difficult, rather than to facilitate them. Physical restraint is not exercised only in the field of psychiatry. The areas of operation where should be discussed the problem of legitimacy, usefulness and appropriateness of physical restraint, do not consist only in hospitals, but also in nursing homes for the elderly, therapeutic communities for drug addicts and nursing homes for people with disabilities related to congenital or early acquired disabilities. An improvement in psychiatric nursing practice, characterized by the renunciation of physical restraint, would be a strong signal in order to spot out the problem also in other operating environments, urging those who work in this field to act with similar treatment practices, rather than restrictive ones. Recently I have been given the opportunity to visit the Psychiatric Service of Diagnosis and Treatment (SPDC) in Trieste, and *Dr. Assunta Signorelli* has showed us the ability to take care of people never using restraint instruments, but using a friendly, human scale approach, where an open dialogue and understanding take the place of a mere deletion of the "symptoms". In addition, people are hospitalized for only one day, or for some days in presence of particular physical

problems.
In the *"Istanbul Protocol - Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment"*, paragraph g) *Review of torture methods*, among other torture methods is listed also: b) *positional torture, suspension by using stretching of limbs, prolonged restriction of movement, forced positioning*; u) *compulsion to attend to torture or other inflicted atrocities*.
The 2010 July the 29th Italian *Conference of Regions and Autonomous Provinces*, approved a document entitled "*Physical restraint in psychiatry: a possible strategy of prevention*". The document, contains seven recommendations to the regions, originated from an intervention by the CPT (*European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment*, which is emanation of the *European Council*), on psychiatric wards in Italy. In the chapter "*Measures of restraint in Psychiatric establishments for adults*", the report says: "The potential of abuse and mistreatment that the use of restraints implies, is of particular concern to the CPT. Unfortunately it seems that in many of the visited structures, an excessive use of restraints is practiced". The document draws up a grading rank of rules to be put in practice, in order to deal with the patient's violence, and include psychological means, verbal interaction and belief, and hold the patient by the hands for a short time. All this is proposed as an alternative to chemical sedation and restraint by straps. The final objective of the Recommendations is that all regions take steps to introduce changes in psychiatric care (knowledge, attitudes, resources, management, organization) that can lead to a stable and safe zero the number of restraints applied in mental health services.
Despite this, the tying by shoulder, obtained by means of a sheet rolled up properly, which stops the patient's back on the bed top, tied behind his headboard, is part of the *Niguarda Department of Mental Health's Protocol* and it is even taught to the students of *Milan's University Specialization School of Clinical Psychology*. Since many years, in a portion of the former *Paolo Pini* asylum, the *Olinda* association organizes cultural activities, music review, theatre, cinema, children's activities, sports activities, various workshops, the *Jodok* bar restaurant, the hostel and numerous other activities throughout the city and with the active participation of users. It would be a paradox if the *Olinda* cultural experience was to be used to cover the disturbing reality of the three *Grossoni* psychiatric wards, that would be not wrong to define similar to an asylum.
Although in recent times campaigns and seminars on the theme of the abolition of physical restraint in psychiatric wards and facilities for the elderly were organized by various organizations, and that in the programs of these campaigns and seminars very firm statements can be read, such as: "The restraint is not a medical act, it is an affront to the dignity of the person who suffers, and it is a symptom of serious inefficiency and ineffectiveness of the services that adopt it", and "Tying a person in a condition of suffering at a hospital bed is an inhuman act, unworthy of a civilized country" and "We propose a proactive path toward a progressive ban of any coercive practice", it seems that despite everything, there is still an underestimating of the urgency of this

"progressive ban on all coercive practices". When you declare that the practical and organizational health care could prevent a rapid ban on physical restraint, it seems that in reality it continues to underestimate the deep human and civil unacceptability of this instrument of physical coercion of inmates. The underestimation of the effects on people tied with this instruments, strictly prohibited since 200 years in the prisons, continues to result in hospitals.

The deplorable situation of the six *Forensic Psychiatric Hospitals* recently became more visible, after surprise-inspections of a parliamentary committee. The videos of the visits, showed by the national television, and the press releases can be found on the web. A parliamentary report had already been made in June 2010, but the photographs show a situation that until now has not yet changed. People held for decades for minor offenses, whose penalty would have expired long time since, if not repeatedly and automatically renewed. Dirt and decay, asylum's instruments and methods of restraint, bottles placed in the toilet's drain in order to prevent rats to come up, neglected physical problems such as those of a person with gangrene in his feet. On 2011 April the 12th, a Romanian citizen has committed suicide at Aversa's *Forensic Psychiatric Hospital*, because his imprisonment was automatically renewed. *Francesca Moccia* of the *Tribunal for Patients' Rights* of *Active Citizenship*, remembers that there is a reform that waits to be implemented from 2008, what requires the closedown of the *Forensic Psychiatric Hospitals*. If we don't shut these places once and for all, we can not talk about de-institutionalization. Close them not in order to transfer their users to other psychiatric institutions, but to give these people a life dignity.

A research (source: *British Medical Journal*) conducted in 6 European countries (Italy, Spain, England, Netherlands, Sweden, Germany), that have closed asylums in the 70s, saw that between 1990 and 2003 an increase in the number of beds in forensic psychiatric hospitals, in psychiatric wards, in so-called safe houses. Supported housing is seen as an alternatives to asylums, as a sign of de-institutionalization, but they are rather a form of institutionalization. Also forced treatments increased. It is not clear the reason why the number of beds in *Forensic Psychiatric Hospital* increased, since there is no correlation between crimes like homicides and de-institutionalized persons.

Erik Olsen of *Enusp* told that recently a survey made in Copenhagen, in a way, has given positive results: about 90% of the people who receive assistance in the socialpsychiatric field, lives independently in their apartments. Only 10% live in the centers/halfwayhouses. But there are still 3 or 4 mammoth institutions, where 173 people live in small rooms (27 x 30 m) and toilets are shared with ten more people. Users with cognitive problems are facing abuses in some of these institutions, a recent television program broadcasted clips filmed with a hidden camera, which has shocked the viewers in Denmark. In any case, says *Erik Olsen*, how can we be sure that people living in institutions do not fall victim of abuse? According to him the institution itself is a violation of human rights, destroys the human agency instead of rebuilding it.

In all European countries lobotomy and electroshock treatments are not prohibited,

although it is widely demonstrated that these non-therapeutic treatments are invasive and destructive. We can not think of a de-institutionalization if we don't remove these practices and if we don't replace them with dialogue, re-socialization, empowering, practices that, as Trieste's Department of Mental Health and other departments have demonstrated, it works fine. It is necessary that human rights laws already enacted will be implemented.

Referring to the psychiatric drugs there are rules of the *Convention on Human Rights*, which require user's fully informed consent, before administering, even if he's disabled. Most psychiatric drugs are prescribed for a long time, sometimes for life, without informing the user on their effects, and without any help in the resolution of his real and existential problems. Akathisia, dyskinesia, are very unpleasant effects and can throw a person in despair. The psychiatric drugs can cause neurological diseases, that sometimes become irreversible. Often the user is encouraged to continue taking the drugs even when he asks to withdraw them, and there are few professionals who help and give directions for withdrawal. *Peter Breggin*, a psychiatrist, working with institutions as WHO (World Health Organisation) and FDA (Food and Drug Administration), wrote hundreds of pages on the harmful effects of psychiatric drugs. *Peter Lehmann*, who tested the effects of drugs on himself during his hospitalization in a psychiatric clinic, has published and continues to publish the results of his research for which he uses pharmaceutical and medical literature. The effect of psychiatric drugs is known, but the billion-dollar business behind it is too big to lose it. *Peter Lehmann* is the first survivor of psychiatry to be awarded with the honorary degree, conferred him by the clinical psychology faculty of the Aristotele's University of Thessaloniki, for his work as researcher and activist in the field of mental health.

A person who starts to take drugs, in most cases will be induced to take them for life, because they create addiction problems. The psychiatric user develops a very strong dependence toward the psychiatric service too. Lack of compliance is in fact intended in it self an aggravation of the disease. Then the conditioning that takes place, goes in the direction of dependence from psychiatric services, of becoming childish and "chronic patient". As long as we continue to administer the drugs in this way, as real chemical straitjackets, we cannot talk about de-institutionalization.

Although in almost all European countries asylums and psychiatric hospitals have been eliminated or substantially reduced, this does not mean that in the new post-asylum structures, asylum-dispositifs have been eliminated. People are, with few exceptions, completely sedated by psychiatric drugs, even though apparently there are implemented programs such as art therapy. The intake of psychiatric drugs is induced also in order to make the user unconscious.

Erwin Redig, a German psychiatric survivor, says: "There are people putting us under pressure to force us to take them (psychiatric drugs). If we do not take them, our changes embarrass them. If this is our case, we must make clear to ourselves that we are swallowing drugs for other people's welfare, because they find us unpleasant if we do

not". "The dispositif of discomfort-complex, that operates in a small residence, acts more broadly in the society". Neuroleptic drugs affect thinking, block the flow of thoughts, and make people flatten. I relate the words of a healthcare professional: "As soon as psychiatric drugs are given to people, they literally get extinguished. To what extend is it fair to cancel the person?" Although in the European countries, the asylum psychiatry and the psychiatric hospitalization of users have given way to communities, the psychiatric institution culture has not changed. Although many examples exist that prove that you can accompany a person in troubles out of his problems, through dialogue and support in the resolution of the objective and material difficulties, and helping him to get awareness of his own rights, these experiments and their positive results continue to be deliberately ignored.

In recent years, many non-profit organizations have flourished, that deal with the so-called social "reintegration" of the psychiatrised person. After the closure of mental hospitals in Italy, several small residential "intermediate" psychiatric facilities were opened, such as group homes, protected dwellings, shared apartments; they often have no substantial difference in rapport to the classic psychiatric institutions. The rule is: "This flat is an ASL (health institution) structure, so if you live in it you must follow the rules of life that the institution gives you". The tenants, that are the users, have no control over the money for household management, bestowed in the form of regional subsidies, and could never say a word in the choice of another tenant; they are obliged to keep the apartment according to the criteria established by the health professionals. Recently a friend who lives in such an apartment was complaining because "they pay for a cleaning lady who comes and sits, giving us orders on how to clean, and when we finish she goes away". The control also extends to external relations. So the typical devices of total institutions are restated in mental health structures who should be the alternative to institutions, either in "intermediate" residential structures or in the "alternative communities". Old asylums heritage as totalitarian relational devices still operates in the structures, and professional's adaptation modes are still the same. The patterns of asylum residentiality are still active. But most of all it is still alive an asylum mentality, therefore it is important for everyone to be aware how much everybody's mentality is crucial in creating or not creating devices that belong to psychiatric institutions; operating devices that constitute a widespread operating module.

A Mental Health Department professional stated that "you certainly can not talk about family-home, where everyday acts are not self-determined by residents". "Residential Intermediate Structures", foreseen in Italy by the 1983 law, should have had the transitoriness as their specificity; therefore they should not constitute either a definite admission or a final place for forced hospitalization; they should have been transitional housing, that could break prejudice and exclusion logics. In March 1999, by a special decree, to the Italian Regions was imposed the definitive closure of the asylums, under threat of strong economic sanctions, because despite the birth, on paper, of the new "local services", mental hospitals were still crowded with patients. Named by the

derogatory title of “asylum residuals”, for these people that nobody wanted, residential structures accounted for an illusion of freedom; they founded themselves to be again in a mental institution. “Many patients”, writes one of them in an autobiography, “have never been so well in terms of comfort, but nevertheless they are in a state of fearful desolation”.

An induced need of security, the defence from a potentially dangerous mind sick person that at any time, during an outbreak, could commit heinous actions against others or against himself; shortly, on the basis of this need and of this false scientific fundamentals, we build the myth of the need of post-asylums psychiatric institutions. If we don’t get reed of the psychiatric prejudice, the “mental health” institution remains. There are many alternatives pursued by individuals, associations or institutions, but they are deliberately ignored. The responsibility for solving the problems of institutionalization, is not up only to psychiatrists or to mental health professionals, but to the whole civil society. Everybody contributes to the asylum mentality. Users as well, who have internalized the psychiatric diagnosis and can no longer live without it.

Mary Nettle, chairman of *Enusp* until 2010, expects an increasing involvement of users and survivors of psychiatry in researches about psychiatry; while they often are excluded or not paid on the pretext that they are not professionals.

Yesterday, I talked with a “*Radio Fragola*” (*Trieste* ex-asylum’s “*Strawberry Radio*”) young operator. To my observation, that usually common people are afraid of people labelled as mentally ill, because after the closure of asylums there is no possibility anymore to lock them up, he replied: “Here it's different, now this different way of relating to the problem is rooted in our territory and we could not do without it”.