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Greek families and users' position on **Adherence to treatment from the human rights based perspective**

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Why human rights?

People with mental disabilities may well be the most vulnerable people in society. Deeply misunderstood and stigmatized, feared even by many of their fellow citizens, they easily fall prey to abuse and gross and systematic violations of their basic human rights.

In order for a country to effectively promote and protect the human rights and fundamental freedoms of its citizens with mental disabilities, it shall, at a minimum, implement mental health instruments that specifically protect the rights of such persons and that are consistent with international human rights conventions and standards.

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The implementation gap

Although Greece has ratified most of the human rights treaties, the implementation gap between international human rights standards that exist on the paper on the one hand, and the impact of those rights on the lives of people on the domestic level on the other hand, is still a sad reality.

The 30yrs old Psychiatric Reform in Greece responded to the needs of only 5% of the mentally challenged population, that is those deinstitutionalized. However, mental diseases are not limited to a firm 5 percent ratio. Affected individuals are continuously growing and the majority of persons with mental disabilities, that is 95% of persons with mental disabilities live with their families who face many challenges due to the absence of government initiatives to offer adequate services and train and empower both families and their challenged loved ones.

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Consequences of the implementation gap

The main consequence of Greece's failure to fill the gap and meet international human rights standards of care for people with mental disabilities - closely related to non-compliance to treatment - has been the LACK OF LONG TERM STATE PLANNING and even today service delivery is not based on service users' rights, needs and values:

- service users are not the source of control over health care decisions that affect them
- there is no shared knowledge nor free flow of information between clinicians and service users
- service users do not receive care based on the best available clinical knowledge, with the system promising excellence and quality as its standard

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- service users and health workers are not aware of the human rights of people with mental and psychosocial disabilities
- service users are not safe from injury caused by the care system
- there is no transparency of information nor anticipation of service users needs
- person-centered therapeutic treatments are quite completely absent
- advocacy, empowerment and training are offered only through NGOs and families and service users' associations.

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Barriers to treatment adherence

- We cannot separate service users' refusal of treatment from what average psychiatric services offer.
- The service users' refusal is only partly related to radical ideological standpoint; to a large extent, it is a reaction against **POOR**, **INADEQUATE, OR EVEN HARMFUL INTERVENTIONS** provided by mental health professionals.
- **LOW-QUALITY CARE**, especially if embedded in NARROW **STIGMATIZING MEDICAL MODELS**, is likely to trigger ideological answers.
- Service users point out a number of **SERVICE SHORTCOMINGS**, such as lack of support offered to people to avoid crises, lack of alternative residential opportunities, misuse of hospitalization and drugs, **AUTHORITARIAN ATTITUDES**, and unwillingness to negotiation with service users to understand their needs and preferences.

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- While the denial of the problem, self-stigmatisation, the difficulty of the regimen, overmedication and the unpleasant side effects of the treatment, the lack of trust in the possibilities of success of the treatment and previous experience that treatment does not work create barriers to compliance, people with mental and psychosocial disabilities in Greece experience a wide range of **HUMAN RIGHTS VIOLATIONS** which are also related to non-compliance.

- **STIGMA** and **DISCRIMINATION** in the health care staff and in the community, the **DENIAL OF THE RIGHT TO EXERCISE LEGAL CAPACITY AND CIVIL, SOCIAL AND POLITICAL RIGHTS. ABUSE, INHUMANE AND DEGRADING TREATMENT**, are also sadly still commonplace.

- **THE IATROCENTRIC MENTAL HEALTHCARE SYSTEM** in Greece where the mental health practitioner is taught to be skeptical of service users' judgment, their self-control, and thus their wishes. Hand-in-hand with this skepticism comes the therapeutic model that says that "we know what is best for them" and that all of our decisions and our expertise, whether they like it or not, are "for their own good". They are decided for them without them.

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- **A PATERNALISTIC AND DEROGATORY HEALTH PROVIDER APPROACH** adds to previous disappointing encounters with the health system, and further decreases the user's incentives to seek help for health problems, creating a demand-side barrier of access and adherence to treatment. When we trump a person's right to make autonomous decisions we send him the message that he is incompetent. We teach him not to trust himself. We teach him that his experience is a pathology rather than an opportunity for self-study and growth.

- **FORCED MEDICATION** which denies a person his right of choice and undermine his sense of self in a way that is metaphorically comparable to the bodily side effects of the drugs themselves. Force to pressure someone to take medication strikes a blow at the foundation of trust in the relationship that may result in non-adherence to treatment.

- **RESTRAINTS USED AS PUNISHMENT AND AS PURPORTEDLY CURATIVE MEASURE** is one of the majors reasons related to non-compliance to treatment

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- **FORCED HOSPITALIZATION** which represents 60% of hospitalizations in Greece and ranks the country **FIRST** in Europe is downright vicious of hospitalization itself and give place to irreparable **TRAUMA** and **FEAR**. It is a basic attack on the person's freedom, on par with getting someone unfairly arrested and is also closely related to non-adherence.

- **ABSENCE OF ALTERNATIVES TO COERCIVE CARE**, such as advance directives, supported-decision making, home-based intervention for first episodes of psychosis gives birth to irrevocable traumatic experiences, fear and unwillingness to comply to treatment

- **TREATING PEOPLE AS OBJECTS TO SAVE - NOT SUBJECTS**, in the name of caring, is often perceived as an exercise of power, and power is not compatible with willingness to compliance.

- **LACK OF SYSTEMATIC PSYCHOTHERAPY, PSYCHOEDUCATION, AND PSYCHOLOGICAL REHABILITATION** intended to increase knowledge of and insight into illness and treatment, to change behaviour, and to obtain skills and meaning in life, are another major reason of non-adherence to treatment.

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- **PROFESSIONALS LACKING THE SKILL, TRAINING OR INSIGHT** to know how to be therapeutic rather than coercive, are highly responsible for non-compliance.

- **IRRESPONSIBLE DE-INSTITUTIONALIZATION** without adequate planning for care and treatment, and without adequate funding for the development of needed community programs of treatment, housing and support, contributes also to non-compliance to treatment

- **INSUFFICIENT STATE'S INITIATIVES FOR THE PSYCHOEDUCATION OF PATIENTS, FAMILIES, AND OTHER KEY PEOPLE IN THE PATIENT'S LIFE IN MENTAL HEALTH RELATED ISSUES**. They all need to learn as much as possible about what mental disease is and how it is treated, and to develop the knowledge and skills needed to avoid relapse and work toward recovery. Patient and family education is an ongoing process that is recommended throughout all phases of the mental illness and if it is not provided it can also be a reason of non-compliance to treatment.

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Removing barriers to treatment adherence

Greek psychiatry must listen in a new way and learn the from consumers' needs. It is a challenging task, which involves giving back power to consumers, discussing conflicts, and accepting contradictions and paradoxes. Consumers stress the need for psychiatric services to reduce or eliminate the use of force, putting into plan practical strategies such as crisis prevention, advance directives, mediation, and de-escalation. Consumers need a healing-focused mental health service system that offers a wide menu of services which address the needs of the whole person in an environment of freedom, choice and equality.

Mental health services should set up anti-discrimination practices, which could reduce community pressure to use force and favor advocacy groups that promote rights, inclusion, and participation. The best way to behave in order to increase adherence to treatment is to be able to connect the client with systems who offer something that is effective. Professionals should try to understand where the consumer is coming from, to understand his needs.

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Psychoses and depression and anxiety and rage are symptoms of a deeper need. Ensuring and protecting human rights should be among professionals' high priorities. Respect and protection of human rights should be part of the therapeutic treatment.

In the Greek reality family remains an important resource for the support and care of persons with psychiatric experience and family participation in treatment, post-discharge appointments and medication adherence can be an important resource in supporting and encouraging people with mental disabilities to make decisions and achieve their goals. Families should be engaged in treatment programmes in order to facilitate post-discharge support, that in other countries, might typically be provided by community workers.

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If we keep doing the same things, we'll keep getting the same results

The Greek family and users' movement rest on the conviction that an equitable health system is a core social institution. Because of its importance, a health system should be reinforced and protected by the right to the highest attainable standard of health and other human rights.

Healthy systems should have certain right-to-health features which are legally binding requirements, not optional extras. Health settings should be places where human rights are realized and fulfilled, not debased and violated.

And the Greek Government must be held to account to ensure that its health system has, in practice, the features required by international human-rights law which respect the dignity and human rights of individuals and protects the interests of people with mental disabilities and their families.

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What could be done?

- **Create a system of human rights oversight and accountability** to ensure rights enforcement in institutions and community-based programs.

- **Adopt comprehensive anti-discrimination legislation** that protects the rights of people with mental and physical disabilities.

- **Establish a comprehensive plan to create and fund community-based services** for people with mental disabilities that (1) provides services for people now detained in institutions who are capable of living in the community (2) builds on the support of Greek non-governmental organizations and families associations, and (3) creates independent community supports for individuals with or without families; Community service programs should include supported housing and supported employment. Independent monitoring programs must be established to ensure quality of care and rights enforcement in community programs.

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- **Build on existing "natural supports" in the community, including peer support and families organizations** - Given the shortage of trained professionals in Greece, and the lack of sustainable funds for important programs, the community system should rely heavily on existing support systems in Greek society. This includes training and assistance for families and peer-support programs.

- **Ensure and support participation by organizations of people with mental disabilities and organizations of families** in policymaking, human rights advocacy, and program implementation through the creation of targeted outreach, training, and civil society support programs for people with disabilities and their families.

- **Establish independent investigation, oversight, and enforcement mechanisms to protect.** Non-governmental advocacy groups should be included in this oversight body. People with mental disabilities and their families, should be trained as investigators; these individuals have unique abilities to understand and gain the trust of individuals subject to abuse.

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- **Improve use of existing staff and hire staff as necessary.** Training and oversight is needed to ensure that current staff is actively engaged in assisting patients. Staff not complying with job requirements should be removed.

- **Create "trauma-informed" services.** The deprivation of control over basic decisions of living, lack of privacy, contact with former abusers, or even association with the location in which previous abuse has occurred, can cause psychologically damaging "retraumatization".

- **Do not let stigma based on mental disability stand in the way of community integration**

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