

Like a bolt from the blue



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The published text is excerpt from:

Nomidou, A. (2021). The Use of Patient Advocates in Supporting People with Psychosocial Disabilities. In M. Stein, F. Mahomed, V. Patel, & C. Sunkel (Eds.), *Mental Health, Legal Capacity, and Human Rights* (pp. 364-377). Cambridge: Cambridge University Press. doi:10.1017/9781108979016.027

[...] Like a bolt from the blue

I never dreamed of becoming a patient advocate or felt it as a calling or as a career prospect. I grew up in a middle-class Greek family in a provincial Greek town in an agricultural area close to the Bulgarian border. It is a quiet town where people seem to live uneventful lives. Languages were my passion, and my dream was to work with words, as a translator. However, needs led me down another road, and this is a road which I am still learning after 40 years.

When I was 14, it became more than obvious that my 16-year-old brother's behavior was something more than typical teenage issues. I remember my father telling my brother that he would send him to “Leros” and me searching in the encyclopedias to find out what “Leros” was. Years later I read that it was “Europe’s guilty secret” (Merrit, 1989, pp. 1,7), “a cemetery of souls”, “a colony of psychopaths” (Gabriel, 1990). I remember hiding my brother from my father and hiding myself from my brother. I remember the smell of blood, the pain, the fear, the shame, and the agonizing question of who was to blame. I remember my family spending so much time striving to disguise vulnerability in order to appear normal.

My brother is one of the most extraordinary persons I’ve ever met. I have always admired his sharp mind, his goodness, his vast interests and his gift for being good in so many fields I could only dream about; a mathematician, a snake whisperer, a fish charmer, a chess player, a skier, a passionate collector of everything

from stamps, coins and vinyl records to frogs and leaves and stones. At the age of 15 his bookshelves were already overloaded with books about spirituality and religion, outer space and the afterlife, ancient civilizations and occult sciences, Freud, Nietzsche, Marx, Einstein, the Greek classics, and anarchist philosophers. I still live with him and his room is still a miniature of a flea market, an attracting place of inspiration.

His behavior continued to attract attention. I remember him “drying herbs” in the oven and hitting us all when we objected, and police called by the neighbors because of the strong smell searching every inch of our house. Knife fights, sirens, police cars, handcuffs for my brother, and injuries for the rest of the family were a frequent show for the neighbors. The police “diagnosed” him with substance abuse. I was declared the sister of a “junkie” and my friends were prohibited by their parents to visit anymore. Gradually, the whole family was ostracized and left to live in frustration, in a new reality. I was in my 20s when I started the visits at police stations, prisons and psychiatric facilities.

From labels and coercion to volition, support and meaning

My brother’s understanding and perception of the real world were frequently considered as sharply and persistently divergent from reality. Sometimes he thought he was Antichrist incarnated while others that he was a cannibal from Papua New Guinea’s jungles. After a long delay – of years, not months - he was diagnosed with schizophrenia; however, he never accepted the label. At that time he was studying nuclear physics. In the eyes of the law he may have upgraded from a “junkie” to a patient; however, in the eyes of society he became a “psycho”. For my parents, the dilemma was where he could best receive treatment. The public sector was not encouraging: there were only eight public mental hospitals in all of Greece, which accommodated over 7,000 patients, more than half of whom were over 50, and 56% of whom would stay more than 10 years (Bairaktaris, 1994, p.108). Was this the most suitable point of contact with the psychiatric health system for a young man in his early twenties? Of course not.

At that time a few private psychiatric clinics were also available. My parents chose one of these with the hope it might be something like the nice clinics we see in films on TV, but it was in this clinic where I first saw chained and otherwise restrained and maltreated young users who begged me in whispers for assistance. In 1992 a Greek law (Law 2071/1992) was adopted that has been described as an important step towards securing the rights of persons with mental illness. However, the cumbersome procedure of involuntary admission, which does not separate placement and treatment, has led to its frequent circumvention by psychiatrists (see European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), 2019, pp. 9-27). This Law, which is still in force, obliges next of kin of persons with a mental illness to contact a public prosecutor, who would launch an admission procedure and transfer by the police to a public psychiatric ward. I was faced with the dilemma of either acting as an informer or accepting that my suffering brother would become a laughing stock, and I opted for the former more than once.

However, I could see only absurdity and injustice in this. Just like the Condemned of Franz Kafka’s “In the Penal Colony”, my brother did not know why he was arrested; the lack of communication was intentional in order to facilitate justice; a hearing was held in absentia of all parties; a standardized involuntary commitment judgment was issued by one single judge “weeks after discharge”; there was no legal representation, no information, nothing. In this process, I was first an informer, then an accessory and later a betrayer (see Greek Ombudsman, 2019 and Stylianidis S. et. al., 2017). Is this the proper way to seek, offer and receive treatment?

In 1998, a psychiatric unit was established in the public General Hospital of my town. My brother was admit-

ted there against his will. Every time my brother was an inpatient there, I felt that nobody should be treated in such conditions, but this situation had become normalized: the Law meant to secure the rights of persons with mental illness was not implemented properly, if at all, but it was nobody's individual responsibility to account for it or to do anything (see Fytrakis E., 2007).

Even though treatment with psychotropic medications was a one-way road that alleviated his so called positive symptoms, reduced frustration, and made living under the same roof easier for the whole family every time he was discharged from this closed-door open unit, I am confident that my brother would have chosen a different way if he had access to other options. When asked about opportunities to exercise legal agency during admission, he says "They respect me. Others have problems because they do not know how to behave. It's important to obey and not to show a desire to leave; when you agree to stay you have better chances to leave because doctors think that you are getting better."

My path to group mental health advocacy

My story is not unique. It is the story of too many. In 1998, I joined some courageous people who wanted to do what the CRPD Committee described twenty years later in GC7 para.12(d)), albeit excluding persons with psychosocial disabilities. We established a local family and user association to assist and empower users to have a voice and take full control of their own lives, and to work to promote and apply supported decision-making processes to ensure and respect the right of users to be consulted and to express their views.

Over the past 22 years, hundreds of people have benefited from our actions - but not my brother. "You can do everything to help people, but without a person's interest in getting better, the help can't work. I want nothing to do with the mad" he says. As a family we wish he could benefit from support and peer groups; however, he has always rejected anything related to "psy". We continue to listen to him if he needs to talk. Sometimes just being there is enough.

The Perfect Advocate

My whole experience to date has shown me that I will always need to develop further skills. Daily hands-on experience on mental health group advocacy practice shows that, in order to change attitudes, skills beyond the legal spectrum are needed; skills that fall within other frameworks, including but not limited to the frameworks of sociology, anthropology, history, political science, social work, diplomacy, communication, cooperation, management, strategy. I recognize that life-long learning will always be necessary to equip me with additional skills to help transform power relations and remove formal and informal barriers to human rights-based recovery oriented laws, policies and practices that promote inclusion of users.

The perfect advocate does not exist, and group advocacy too depends on politics and policy prioritizations, and a plethora of other factors. There are still many countries balancing between old embedded beliefs and new obligations for change, where professional advocacy is not yet a legal entitlement, where no formal financial assistance for group advocacy and support services is available, and where both the former and the latter are mainly, if not exclusively, resourced by passion, commitment and resourcefulness. I have learnt to operate in such environments, to inspire hope to users and families and remind the State and other key stakeholders of their obligations.

It has been a long road, but I have finally started to be the mental health advocate I wish I had met 40 years ago: one of those advocates who according to Lewis (2017) "speak up about what they care about and care about what they speak about." [...]

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