



# POSTPSYCHIATRY'S CHALLENGE TO THE CHEMICAL TREATMENT OF MENTAL DISTRESS

When we name you a 'schizophrenic', we take away your speech and your ability to name yourself, we obliterate you. The moral position that we must adopt is one in which we bear witness and resistance. To bear witness means accepting the reality of lives harmed and damaged by many things, including psychiatry. We can no longer deny this.

***P. Bracken and P. Thomas Postpsychiatry***

The reduction of peoples distressing life experiences into a diagnosis of schizophrenia means that they are condemned to lives dulled by drugs and blighted by stigma and offered no opportunity to make sense of their experiences.

***Jacqui Dillon Chair of the UK Hearing Voices Network***

It is open to question whether schizophrenic patients, with their lack of insight into their illness and their cognitive deficiencies, are able to assess their own situation and to evaluate and describe their psychic state and the positive/negative effects of the medication given to them.

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A very special thank you to all my interviewees who participated and who shared their experiences with me.

## ABSTRACT

People who take psychiatric medication often have a very different view and experience of their medication than those who prescribe it. This thesis explores the discrepancies between the experiences of users and prescribers in an attempt to find out how we deal with these differences. It does this from a postpsychiatric perspective, which is critical of contemporary psychiatry, not as an opponent, but with the viewpoint of moving beyond current practices. In exploring these discrepancies, this thesis gives voice to those who are normally silenced by the current medical model of psychiatry, which insists that those diagnosed as schizophrenic suffer from a brain disorder and/or chemical imbalance.

A search through the research literature spanning five databases from 1950 to 2012 was performed looking for research focusing on the subjective medical experiences of those labeled schizophrenic. The research literature provides tangible evidence that the subjective experience of psychiatric medication from those labelled schizophrenic plays a small role in that only 14 articles were found. A counter history of psychopharmacology is also introduced in an attempt to counterbalance the gaps left out by the dominant discourse. The counter history shows that when psychiatric drugs first appeared, psychiatrists initially experienced the way these drugs worked as being in agreement with how service users experience them, including the seven interviewees here. The counter history also indicates that the pharmaceutical industry played a major role in transforming psychiatry's initial medical narrative into the one we recognize today.

For this thesis, seven people labeled schizophrenic participated in qualitative interviews, giving voice to their experience of taking psychiatric medication. Three accept medication, two doubt its efficacy, and two are off medication completely. The voices of the interviewees introduce a world of context, meaning and understanding and show that madness is multifaceted and complex but understandable. The narratives of their medication experiences challenge the current psychiatric belief system. The voices of the seven interviewees show that their medication experiences cannot be removed from the context of their lives. But this challenges psychiatry's current discourse, which tends to symptomize or downplay the experiences of service users. Depending on how they themselves experienced the dominant medical discourse, the service users dealt with its variation from their own experiences in a variety of ways.

The narratives of the interviews indicate finally that there is a gap in the production of knowledge, and that if we are to move beyond the current psychiatric paradigm as proposed by postpsychiatry, we cannot continue to ignore the voices and thereby the rights of those whom psychiatry treats.

# POSTPSYCHIATRY'S CHALLENGE TO THE CHEMICAL TREATMENT OF MENTAL DISTRESS

## INTRODUCTION

One of the most contentious debates in the field of mental health is whether mental distress is biogenetic or whether it results from traumatic lived experiences. Some might argue that it does not matter, but anyone who has ever received a diagnosis for mental distress knows that it does. Treatment is determined by those making the diagnosis, and psychiatric diagnoses have social consequences, especially the more severe ones. Indeed there are those who argue that they can be catastrophic:

*"Diagnosing someone with a devastating label such as 'schizophrenia' or 'personality disorder' is one of the most damaging things one human being can do to another."*<sup>1</sup>

Nor can one ignore that mental health is the only field where one can be forced to abide by the treatment imposed according to the diagnosis that has been given. It would seem absurd to contemplate forced insulin treatment for diabetics or to impose antibiotic treatment on people suffering a bout of pneumonia if they do not want it. That treatment can be forced upon mental health patients makes psychiatry unique in relation to other medical specialties. Moreover, psychiatrists play a major role in the judicial system and act as enforcers/arbiters of a law that some argue allows for legalized breaches of human rights. For example Tina Minkowitz, lawyer and expert on the Convention on the Rights of Persons with Disabilities (CRPD) writes:

*"I have also analyzed some of the types of harm that flow from forced psychiatry, [...] which support a conclusion that the complex harm of forced psychiatry as a whole amounts to torture."*<sup>A</sup>

UN Special Rapporteur on Torture, Juan E Méndez (2013) would appear to be in agreement for he has stated that:

*"It is important that States review the anti-torture framework in relation to persons with disabilities in line with the CRPD. States should impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs, for both long- and short- term application."*<sup>2</sup>

Although Denmark projects itself as a staunch proponent for human rights, the country's record within mental health treatment suggests that the truth is more complex. In Denmark, approximately one in five

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<sup>A</sup> (See Annex III to report of expert meeting on torture and persons with disabilities, on UN website).

patients is force treated, with forced medication being the most used treatment (6043 patients in 2011), followed by being placed in belts (5880 patients in 2011)<sup>3</sup>.

A large proportion of patients approximately three-quarters will choose within a year to stop taking psychotropic drugs<sup>4</sup>. The group who adheres least to psychotropic medication despite medical supervision is those diagnosed as schizophrenic with approximately 50% in general being non-compliant<sup>5</sup> and studies have shown that up to 40% stop taking their medicine after one year and 75% after two years. This non-compliance appears to have changed little over the years since psychotropic medication was introduced with the major factors resulting in non-compliance being a poor relationship with the treating psychiatrist, discrepancy between patient belief system of causation and that of the treating clinician, side effects and, more recently, the lack of supporting evidence to confirm diagnosis<sup>6</sup>. Another possibility is anosognosia, the person does not view themselves as ill. In a review, 10 of 14 studies that examined this and medication nonadherence in schizophrenia reported that the two are strongly associated.<sup>7</sup> A Danish thesis, looking at the relationship between compliance and psycho-education, showed that there appears to be no definite connection.<sup>8</sup> Interestingly, a study in 2004 showed that 71.4% psychiatrists expressed a willingness to take antipsychotics versus 35% of the non-medical professionals if they were to suffer from schizophrenia<sup>9</sup>. This contrast is perhaps indicative of their belief in their role as alleviators of mental distress, or loyalty to their own praxis. In contrast the mean non-compliance rate for people suffering physical disorders is 24%<sup>10</sup> For example people with type 2 diabetes in one study were 25.25% likely to be non-compliant and a large UK study (2012) showed that 29.4% suffering type 1 diabetes had a record of either not attending appointments or being medication non-compliant which was linked to increased mortality<sup>11</sup>.

Thus it is clear we have a paradox, a situation where a group of psychiatric patients, if given the choice, would not take medicine and a society which has in turn created a system to condone forcing noncompliant psychiatric patients to undergo treatment. Today forced medication is performed by injecting the patient with the psychotropic drug but when these were less available in the 1960s<sup>12</sup> giving non-compliant patients the drug surreptitiously was actively promoted as can be seen by the various advertisements from that time, for example:

*"How can you help him if he refuses medication?*

*Tasteless and undetectable HALDOL (haloperidol) Liquid Concentrate may make it possible for you to reach even highly recalcitrant psychotic patients. The liquid concentrate form of this potent antipsychotic agent is not only tasteless, but colorless and odorless as well. It can therefore be added without patient detection to any routine vehicle pleasing to the patient's taste, including fruit juice and even water."*<sup>13</sup>

However the vast majority are persuaded to take psychotropic drugs in the belief that they will help, even cure which has contributed to pharmaceutical industries being regularly featuring on the Forbes list of most profitable organizations. The pharmaceutical industry also has the dubious honor of being recipients of the largest fines ever levied overtaking the arms industry in terms of illegal praxis with a large proportion of the illegal activities involving psychotropic drugs particularly antidepressants and antipsychotics<sup>14</sup>. This has in part come about by the huge demand from consumers seeking alleviation from distress through the quick fixes and magic bullets of chemical solutions.

Standards and standardization within this perspective play a central role in that time costs money and a productive psychiatry equates to a successful business. Psychiatry has always had an intimate relationship with economics from the era when the 'mad' threatened work ethics in the form of idleness leading to the creation of large asylums. Today, the medicalization of deviancy and psychiatry's role in social control is closely connected to the pharmaceutical industry and the concept of the chemical imbalance of the brain.<sup>15</sup>

Present day politics and New Public Management policies dictate a preference for clear cut problems which can be linked to people's social security number which in turn dictate what service(s) is available that can then be documented and later measured and evaluated for efficacy. Within this context medicalizing mental distress is preferable to viewing distress as coming from unwieldy social contexts. Patients can have a legitimate, acceptable problem and identity, families can be freed from blame becoming instead part of the help-systems and professionals can cultivate an expert role.<sup>16</sup> However, the consequences of such an approach are twofold; the growth of authoritarian administrative practices alongside liberal governmentalities heavy reliance on self-management and the development of what Nicolas Rose terms *psy-knowledge*<sup>A</sup>.

Yet also true of our times is a revival of ideological, holistic and socially orientated understandings of distress represented by the growth of support groups many of whom are voluntarily run and found in many walks of life including (ex)patient networks. These networks increasingly play a role in influencing organizations serving their needs, be it from an oppositional angle such as the Hearing Voices Network (HVN) who reject the schizophrenic label and the medicalization of their misery, to groups insisting that their situation be acknowledged as a valid illness. For example fibromyalgia which despite continued skepticism from some doctors has now, due to network pressure, been acknowledged as an independent illness worthy of its own diagnostic placement in the ICD 10 and, importantly, no longer defined as being of a psychological nature. Thus it becomes clear that when different interests are at stake different viewpoints will be in action regarding what in theory is the same object or a multiplicity of realities such as described by Annemarie Mol in her ethnography of disease. By analyzing atherosclerosis through various modes of interactions of different agents, she shows that many different and potential realities about atherosclerosis as a singular object can exist. This multiplicity of realities exists within psychiatry too but the conflicting nature of its multiple ontologies in cases like schizophrenia along with the social consequences makes this more obvious as expressed by networks focusing on their role and practice who in turn influence the knowledge of the dominant power structures.

To expand further on the influence these networks can have, one can look at those who use or have used psychiatry, their families and a growing body of professionals who have increasingly begun to question the scientific validity of the psychiatric bio-genetic paradigm and the ethical dilemmas this poses when the validity of psychiatric drug treatment is questioned. This discrepancy between the psychiatric medical perspective and that of those who are critical to psychiatry has perhaps been most clearly demonstrated in

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<sup>A</sup> Meaning the discourse produced by the psychologists, psychiatrists and other professionals for knowing, understanding and managing the individual.

Denmark, by the "Kors" (Cross) campaign –a campaign launched by LAP<sup>A</sup> and Død i Psykiatrien<sup>B</sup> highlighting the fact that the average life expectancy of a psychiatric user in Denmark is 22 years shorter than the normal population and that many young people are dying suddenly many with measured excessive amounts of psychiatric drugs in their blood. For example, a study from Denmark showed an overrepresentation of deaths in the 18 to 30 age group of in particular those labeled schizophrenic<sup>C</sup> something psychiatry perhaps views more pragmatically:

*"The treatment of some of the patients in supported psychiatric housing facilities is very complicated, and lack of treatment response, use of psychiatric poly-pharmacy, and sudden unexpected deaths are common problems."*<sup>17</sup>

Those it affects view it more personally however, and although the campaign was regarded in 2010 as highly provocative, when it ended in June 2012 it had inspired research into why psychiatric patients are dying earlier than others and started generalized questioning of the praxis of Danish psychiatry. The media has been particularly investigative as of last year, kick-started by the Glostrup Case<sup>D</sup> resulting in psychiatry becoming a major focus area also politically. Psychiatrists have, since the latter half of 2012, begun to enter into the public arena to defend their position as experts on the issues of mental distress.

*"Psychiatry is a medical specialty [...] we have not yet heard of any other medical specialty where the doctor's professionalism is undermined, who for example would suggest that health specialists other than doctors should debate the medical treatment of diabetes or high blood pressure?"*<sup>18</sup>

While other media discussions have centered on the insistence of a biological explanation:

*"It is important to point out that the clinical symptoms of people with psychosis are related to the complex biological processes in the brain. [...] most patients, who suffer from schizophrenia, have disturbances in one of the brain's chemical systems, the so called dopamine system and all antipsychotics work by inhibiting this dopamine system"*<sup>19</sup>

Critics of such positions argue that this is built on a belief system involving two primary assumptions: that deviant behavior and mental distress are present due to biological abnormalities and that chemical interventions can fix this. Proponents of the recovery movement would on the other hand, question the exclusivity of one group being the experts stating that the patient too is equally an expert. Others such as Uffe Juul Jensen and Mol view medicine including psychiatry as not being built upon essentialist foundations but being governed by clinical standards that are contradictory. Some view their madness as being a part of human diversity to be celebrated such as Mad Pride and Mad Chicks, while still others such

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<sup>A</sup> Landsforeningen af Nuværende og Tidligere Psykiatribrugere (national organization, founded in 1999, of Danish (Ex-) Users of Psychiatry)

<sup>B</sup> National organization for family members who have lost a loved one due to psychiatric care.

<sup>C</sup> For every one woman who dies in the 18 to 30 age group over 14 are dying in the group homes for men it is over 10 for every one young man in the normal population.

<sup>D</sup> The psychiatric centre Glostrup has for a number of years been over-medicating patients with the antipsychotic Zyprexa many receiving 120mg/day or more when the maximum dose is 20mg/day, as well as using Midazolam not approved for psychiatric use in potentially lethal dosages <http://politiken.dk/indland/ECE1664104/hver-anden-patient-bliver-massivt-overmedicineret/>

as the HVN say madness is a product of trauma and that symptoms are meaningful and related to life stories.

However, it is the medical model of psychiatry which continues to be the dominant paradigm and has been since the 1980s when psychiatry was successfully restructured. This occurred at a time when antipsychiatry and its supporters saw mental illness as not being embodied in the individual, but as a product of oppressive social conditions highlighted by, in particular, four main thinkers. Michel Foucault with his emphasis on power, and control, Erving Goffman, whose ethnographic study of psychiatric hospitals emphasised the horrors of brutal and ineffective treatments where patients were rendered dull and inconspicuous. R. D. Laing whose seminal work on schizophrenia in which he argued that the impossible binds placed by family and society on the person was the cause of the patients' pathology and finally, Thomas Szasz whose rejection of an illness paradigm on grounds that there is no evidence, referring to mental illness as being a myth and instead argues that mental illness is a social and ethical problem. But despite having a profound influence then, they, along with the (ex)user organizations were unable to successfully oppose psychiatry's highly focused repositioning and revamping of the medical model of psychiatry started by the DSM-III in 1980. Prior to that psychiatry had had a more eclectic predominantly psychoanalytical approach to mental distress. But with the proliferation of talking therapies emerging in the 1970s, the stinging attacks by antipsychiatry which exposed dehumanization in the asylums and the inability to be able to agree on who was mentally ill or not,<sup>20</sup> as was publically demonstrated by the Rosenhan experiment (1973), compromised psychiatry's credibility and placed it in a crisis<sup>21</sup>. Many viewed this crisis as a failure of diagnostic reliability and the solution was to increase reliability through standardization simultaneously strengthening its claims to being scientifically based resulting in the DSM-III.

With the introduction of the DSM-III orchestrated by Robert Spitzer, psychiatry redefined its expertise role by disconnecting diagnosis from etiology that was mostly psychodynamic, to a cataloged, descriptive approach to diagnoses. Thus by classifying symptoms into discrete disease entities representing organic pathologies located in the body, a biomedical model of psychiatry came about.<sup>22</sup> Many psychiatrists would only think of physiological causes, although most psychiatrists, at least officially would claim some multidimensional bio-psycho-social etiology. This was further cemented with the DSM-IV in 1994, however, the DSM-V released May 2013 is contrary to previous versions being subjected to criticism not least by the former Chair of the DSM-IV, Allen Frances<sup>23</sup>.

Though there has been a rise in the number of (ex)patient and family organizations critical of psychiatry not as many professional organizations exist which are manifestly critical. In Denmark Galebevægelsen established in 1979 consisting of both (ex)users and professionals is visibly critical<sup>24</sup> however in terms of visibility it has largely been replaced by LAP. There is however one organization based in the UK which has entered into the arena critiquing psychiatry and interestingly they are doing so from the inside in the form of the Critical Psychiatry Network (CPN). It is an organization primarily for psychiatrists, trainees and medical students and it is from CPN the concept of postpsychiatry has been introduced. Originally the term postpsychiatry came from the psychiatric survivor Peter Campbell when he, in an anthology 1996, tried to imagine a world after psychiatry. This inspired two psychiatrists Patrick Bracken and Philip Thomas who coined the word in the late 1990s. They view postpsychiatry as agreeing with, and sharing commonalities of critical psychiatry but endorsing aspects which go beyond critical psychiatry. Particularly

with regards to Cartesian dualisms present in body-mind, mind-society and body-society which is very prevalent in psychiatry with its inability to fully engage in the encultured and embodied reality of people experiencing mental distress. The CPN supports survivor activists and service users who campaign against the role of the pharmaceutical industry in psychiatry and has actively supported the campaign for the abolition of the schizophrenia label. However, it is its formal links to the HVN, in other words, the joining of forces between psychiatrists and people who have typically been labeled schizophrenic which provides an intriguing combination. As an organization primarily for psychiatrists they actively encourage sympathetic non psychiatrists to join the HVN which then enables them to have access to the CPN forum and articles.

Coming from the HVN I am inspired by the CPN and in particular postpsychiatry, which views psychiatry, as do other historians, as being guided by a modernist paradigm which seeks to frame human problems in a scientific and technological manner. Distress<sup>A</sup> therefore from this modernist perspective, becomes a technical problem to be dealt with scientifically as expressed in the medical model of psychiatry, and such things as meaning, values, relationships and so on, are rendered as secondary. Thus postpsychiatry seeks answers and inspiration by looking to postmodernist thought which attempts to move beyond the dichotomies characteristic of the antipsychiatry era and engage fully in a constructive *collective* manner with the concerns of those who use psychiatry. They state, *"if psychiatry is to be genuinely 'evidence based' and sincere in its commitments to work with the service user movement, it will have to move beyond the hold of the current paradigm."*<sup>25</sup>

In light of that statement I wish to propose the following problem formulation: **From the perspective of postpsychiatry how do we deal with the discrepancies between traditional psychiatry's medication experience and that of the service users? And, is it possible through analyzing these discrepancies, to contribute to developing postpsychiatry?**

## THE APPROACH

### HOW DO I WANT TO EXPRESS MYSELF THROUGH THIS WORK?

I am aware that I am not neutral and rather than attempting to be impartial I will be aligning my thesis with other thinkers who approach psychiatry from a critical position thus remaining congruent to myself. This does not necessarily detract from my ability to acknowledge the positive aspects within psychiatry however, by the very fact that I am analyzing the subjective experiences of people who take these drugs, I am automatically situating myself as an opponent to psychiatry. For the unwritten rule which has existed ever since I started to work as a psychiatric nurse in the late 1980s has been not to say anything critical about psychiatric medication, at least not in public.

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<sup>A</sup> I will be using a variety of expressions to express mental distress to denote the many different ways of describing this phenomenon in the literature and amongst those who use services.

Should one do so it tends to be counteracted from a belief that there is often no choice:

*"Here we cannot scratch our heads while we speculate on what is wrong with the patient. [...] because it is completely unethical and irresponsible to let them walk around in that state"*<sup>26</sup>

Or in a derogatory light:

*"We hereby call on a little soul-searching before such claims breathes life into an anti-psychiatric debate, we hoped was abandoned".*<sup>27</sup>

Or even as potentially dangerous:

*"Your links are controversial<sup>A</sup>, and your information harmful for the [mentally] ill, if they were to believe in [your] references."*<sup>28</sup>

## METHODOLOGICAL STRUCTURE

I have chosen to do qualitative interviews with people who are, or have been, on psychiatric drugs all of whom have been labeled as schizophrenics. I interviewed in all, seven people five men, **Lou** (40), **Ben** (21), **Zac** (38), **Joe** (51) **Leo** (38) and two women **Mia** (43) and **Pat** (48). Lou and Ben I interviewed together in the presence of **Kat** a Worker who accompanied them and who works individually with Ben as part of his multidisciplinary team and runs the Voice Hearing group that they both attend. My interviews were done in The UK and in Denmark and 5 of the interviews were recorded in English. One of my Danish participants was equally at home in English and Danish so we spoke English. I transcribed them and the last two interviews which were done in Danish I both transcribed and translated. The interviews ranged from 50mins to an hour and 20mins. In all cases I made my position clear by informing them that I view myself as a psychiatric survivor, that I am active in the HVN and that I no longer take psychiatric drugs. The reason is twofold. I want to be as truthful as possible, and as the interviewer I am the measuring instrument and it is important to know from where I am measuring. But also by sharing that I too know what it is like to be a 'medicated schizophrenic,' I can perhaps open the door to a more candid portrayal of the psychiatric drug experience from my interviewees.

Of the 7 chosen, 3 are content to take their psychiatric drugs, 2 are still on their drugs but no longer satisfied with them and 2 no longer take them. I want to get as broad a range of opinions as possible, hence my choice of participants. By choosing people who are positive concerning their drugs, I am deliberately choosing people who can potentially challenge my critical stance on psychiatric medication. I hope by doing this I open the data and interpretation to a wider scrutiny. By choosing seven interviews in the limited amount of space available I am aware that I cannot go into the depth that these interviews warrant, nevertheless I do hope the richness of their stories is revealed.

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<sup>A</sup> The link referred to here was Robert Whitaker's book **Anatomy of an Epidemic**

## METHOD CHOSEN

I chose to interview using an unstructured, naturalistic approach inspired by J.M. Johnson's In-depth Interviewing technique<sup>29</sup> which is used "*in conjunction with data gathered through such avenues as the lived experience of the interviewer as a member or participant in what is being studied...*"<sup>30</sup> where I try to, as recommended by Johnson, establish trust and rapport, involve myself actively where some level of reciprocity is present. Johnson states that the interviewer should be highly self-reflective and make a conscious effort to observe their interactions with others, something I have tried to do.

In analyzing my data, I have used the computer program Nvivo, mainly to help categorize themes based on the fact that having 7 people and limited space I want to ensure the messages from each interviewee is not lost and through categorization introduce some structure in what is essentially unstructured. My analysis is guided by the principles of narrative and feminist research methodology and the reasons I have chosen this are:

1. By opting for an unstructured in-depth interview, all of my interviewees have told of their experiences in a naturally narrative manner making use of chronology while attempting to explain to me their interpretation of their world. Thus each story is rich in personal meaning and metaphors; it's subjective and is not to be understood as a 'factual truth'. Their stories, in the narrative context can be seen as the social products produced in specific contexts, which are circumscribed by the historical, cultural and social contexts of the person's life story and therefore part of their identities.
2. I have chosen to use feminist research principles<sup>31</sup> even though this is not a study of gender, because so many of the issues at stake resonate with the problems that have and still face women when it comes to sexist, androcentric research which is assumed will be useful for women. This bears similarity to psychiatry often described as a patriarchal system, which produces research assumed to be useful for their patients without involving them. Another typical problem facing women is the issue of ignoring or forgetting gender as perhaps playing an important role which can equate to in psychiatry, ignoring or forgetting the social context or life story of the patient as perhaps similarly playing an important role. Likewise gender stereotyping can be equated to patient stereotyping.

## REVIEW OF THE RESEARCH LITERATURE

I chose to do a review of the research literature to test my assumption that research into the subjective experience of taking psychotropic drugs as a diagnosed schizophrenic would be under represented. This assumption was based in part on the research on the subjectivity of madness by the psychologists John Read and Jim Geekie, in their book, **Making Sense of Madness**; in particular their review of the literature on how much subjectivity has played a role in research relating to schizophrenia. They<sup>32</sup> observed that from 1966 MEDLINE, 1806 PsychINFO until mid-2008 the total research literature on schizophrenia addressing subjective experience equated to 0.17% MEDLINE and 0.33% PsycINFO. This is one of the clearest indicators of the divide between those who use the psychiatric services and the power structure that lies implicit within the paradigm of psychiatry. Psychiatry has objectified those to whom it treats, rendering them as passive agents upon whom they can act. This is not a new praxis as can be seen in the history of somatic medicine, but where this has changed dramatically in recent times psychiatry is still rooted in the belief system that they are the purveyors of 'the truth' rather than a truth.

My review of the literature spanned from 1950 to the end of 2012 using the databases PubMed, Cochrane, PsycInfo, MEDLINE and Embase. Starting in 1950, even though psychotropic medication formally took off on a large scale in 1954, meant I could cover a possible pre-experimental period in case there were any relevant studies.

Primary search string was "Schizophrenia"

Secondary search string (2) was "Subjectiv\* or personal experience\* or phenomenolog\* or subjective experience\*"

Third search string (3) was "Medicine or anti-psychotic\* or antipsychotic\* or neuroleptic\*"

Forth string was(4) "Qualitative"

	<b>PUBMED</b>	<b>MEDLINE</b>	<b>EMBASE</b>	<b>COCHRANE</b>	<b>PSYCIINFO</b>
Schizophrenia	100939	95673	143985	8608	91630
Schizophrenia + (2), (3), (4)	10 (4)	11(4)	26(14)	0	5(2)
Schizophrenia and drugs (3)	33873	23296	38671	3865	16599
Percentage	<b>0.01%</b>	<b>0.02%</b>	<b>0.04%</b>	<b>0.0%</b>	<b>0.03%</b>

I went through the few research articles that were flagged and removed those that did not fulfill the criteria resulting in 24 articles of which 10 were repeats so there were only 14 articles which involved the subjective experience of psychotropic drugs through qualitative or semi-qualitative questionnaires. Even though there will naturally be research articles which I will have missed it is still possible to conclude that the subjectivity of those consuming the psychotropic drugs is extremely underrepresented in the research literature and would support my hypothesis that in terms of knowledge production one group dominates. That does not mean that the other group is silent for if it were, there would be no discrepancy between the established knowledge and that of the service users', instead service user knowledge regarding medication comes about through other channels and perhaps the most visible sign of this discrepancy is indicated by the fact that many of psychiatry's customers are forced customers. So what is it that is stopping user knowledge from being acknowledged? What forces are in place to keep this knowledge out of mainstream society?

To find some answers part of my methodology will be to unearth the other psychopharmacological story and to do so it will be relevant to go into the history of psychiatric drugs. Foucault argues that we should not consider the past history as a fixed entity we should view it as multiple overlapping and contesting histories and that modern history is an invention of our own time, in that we are constantly reconstructing the past to suit the interests of the present<sup>33</sup>. Likewise Foucault tells us that historians and history speak from different places. Typically the historian speaks from a place of authority supported by an institution like the university or a museum i.e. positions of authority but these positions will shape what kind of history is recorded, how it will be fitted together to create a whole yet there are gaps. It leaves out material which has been lost or not collected such as the oral history of indigenous people or the peasants who could not write and so it was their masters who recorded history 'for them'. Similarly with regards to psychiatry its medical history as seen today has been shaped from a place of authority but that does not mean a contesting history does not exist.

# A COUNTER HISTORY OF PSYCHOPHARMACOLOGY

Looking at the biology of mental illness, research has attempted to locate where it goes wrong and here it has long been assumed that mental illnesses are due to neurotransmitter defects. Indeed, the main focus of psychiatry has for the last 50+ years been based around treating these assumed neurotransmitter defects.

## CHLORPROMAZINE

Chlorpromazine was introduced to the unsuspecting world in 1953 and approved by the FDA in the USA 1954 just four years after Egas Moniz received the Nobel Prize for the invention of lobotomy. Chlorpromazine was a treatment for major mental illnesses predominantly schizophrenia and functioned by blocking dopamine receptors; however the way it was seen to work then was different to the way it is seen to work today. It was originally synthesized in 1950 by Rhône-Poulenc a French pharmaceutical company primarily interested in antihistamines and their usefulness in surgery, something they had observed since the 1930s. Rhône-Poulenc had many prominent researchers working for them and it was in 1947 one such researcher Paul Charpentier, discovered the phenothiazine antihistamines, a potent group of antihistamines which did not have as many side effects as the previous ones and from which chlorpromazine was ultimately derived. Many drugs have since been derived from the antihistamines including all antipsychotics and antidepressants.

Rhône-Poulenc had two other prominent researchers, Pierre Huguenard and Henri Laborit as part of this interest in using antihistamines in surgery they invented the Lytic cocktail<sup>A</sup>. It was when this cocktail was first used in vitro for an operation that its ability to create a state of relaxation, almost indifference, was observed.

In early 1951, Simone Courvoisier started to test these new compounds and her testing is recognized as one of the first known industrial tests on behavior to screen for pharmacological properties. She used rats, a rope, a platform and food and exposed the rats to shock treatment from which they learned to avoid as well as being trained for food rewards. She discovered that rats, when on these drugs, stopped responding to the food reward and did not climb the rope to escape the shock even though they knew it was coming, they seemed completely indifferent and this extreme reaction intrigued Courvoisier. What Charpentier had done was chlorinate some of these antihistamine compounds to increase their potency and the most powerful combination was that of chlorinating a compound called **promazine**. Thus he created what is known today as **chlorpromazine** and what was to become the first known antipsychotic.

Chlorpromazine was surprising in its characteristics. For it had an effect on the sympathetic nervous system - the "flight or fight" system - by reducing epinephrine's effects and causing relaxation, it had a marked cardiovascular effect on animals, it potentiated the effect of barbiturates and it was an anti-nausea. Chlorpromazine also affected the rats in the rope climbing experiment even more than all the

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<sup>A</sup> A mixture of drugs injected intravenously to produce sedation, analgesia, amnesia, hypotension, hypothermia, and blockade of the functions of the sympathetic and parasympathetic nervous systems during surgical anesthesia.

other compounds and Courvoisier summarized that the rats failed to respond, not because they were sedated or their coordination impaired, but because they seemed to be indifferent.

In 1952 the news of chlorpromazine had reached the largest psychiatric hospital in Paris, Sainte Anne which had room for 4000 patients. Jean Delay a neurologist had just been awarded professorship having competed against Henri Ey, and Henri Baruk, two psychiatrists who worked in the asylums. Interestingly, had Baruk won the position Chlorpromazine might have taken a completely different route.

Sainte Anne had long stay wards housing about 200 male and female patients in separate wards. Pierre Deniker, a psychiatrist, was in charge of the male ward. He had heard of chlorpromazine and proceeded with the support of Delay to try it out on his patients in the locked ward.

The results were extraordinary with descriptions of patients who seemed to wake up from their “madness” which they had been immersed in for years and for the first time conversing apparently normally. Patients became much calmer on Chlorpromazine which resulted in another very noticeable effect, the noise level fell, so much so that it was noticeable for the people who worked or lived near the asylum. It quickly became apparent that chlorpromazine was not sedating the patients in the usual fashion for though they appeared to be asleep, they could easily be roused and were able to react and respond quickly compared to patients sedated with other drugs. Delay and Deniker rushed out a series of scientific papers and publications stressing the importance of chlorpromazine on manic and delirious patients as well as stating that this drug was an anti-schizophrenic.

This shocked Baruk who said, how can they be anti-schizophrenic when they produce another form of schizophrenia, namely catatonia?<sup>34</sup>. Baruk had been researching the catatonias, a syndrome of psychic and motor disturbances, which was associated with certain schizophrenias and his experiments on animals using Chlorpromazine showed that it appeared to cause catatonia. This confirmed Courvoisier’s observations of the laboratory rat’s indifference to food and shock and so from his perspective Chlorpromazine caused schizophrenia rather than treated it. Delay and Deniker’s initial description would appear to support Baruk:

*“Seated or lying down, the patient is motionless on his bed, often pale with lowered eyelids. [...] he rarely takes the initiative of asking a question; he does not express his preoccupations, desires, or preference. [...] The apparent indifference or the delay in response to external stimuli, the emotional and affective neutrality, the decrease in both initiative and preoccupation without alteration in conscious awareness or in intellectual faculties constitute the syndrome due to treatment”<sup>35</sup>*

The way it was viewed then, is very much on par with how many psychiatric patients appear to experience these powerful drugs today. For example, a young psychiatrist Cornelia Quarti tried Chlorpromazine in vitro November 1951, before it became commercially available as a psychiatric drug. She was injected intravenously with an unknown amount by Leon Chertok a French psychiatrist, and her comments were voice recorded. Laborit later reproduced Quarti’s own written account and since it is extremely rare for psychiatrists to voluntarily try the same treatment they give or indeed force upon their patients, this is one of the few unique accounts from a psychiatrist brave enough to volunteer. Her description was recorded and taken seriously as a scientific experiment; here are some excerpts from Quarti’s own account:

*"I begin to feel that I am getting weaker and weaker, it is very difficult and harrowing. At 12h10, one of the assistants tries to...hypnotize me. I gather all my energies to shout at him (so it seems to me): "No, you are bothering me." In fact judging from the voice recording I transmitted a weak and monotonous voice....At 13h...the painful feeling of imminent death gives way to a euphoric calm. I still feel I am dying, but this leaves me indifferent....in the evening, I am still very tired and must stay in bed... The speech difficulty continues.... The lassitude and speech disorders persist for a few days to disappear progressively."*<sup>36</sup>

Another psychiatrist who has tried Chlorpromazine as student to earn money, was the former head of Center for Studies of Schizophrenia Loren Mosher:

*"I have tried the antipsychotics ... chlorpromazine. They're terrible! [...] ... I was a medical student who needed money ... I was pretreated [at home] for a day with chlorpromazine, which meant I spent the day on the couch; I couldn't move, I couldn't move. [...] I felt like somebody had injected concrete into my muscles."*<sup>37</sup>

Psychiatrist David Healy in 1993 asked volunteers to try either randomly an antipsychotic, or a placebo and among those who volunteered was psychologist Richard Bentall:

*"For the first hour I didn't feel too bad. I thought maybe this is okay. I can get away with this. I felt a bit light-headed."*

He was then asked to fill in a form:

*"I looked at this test and I couldn't have filled it in to save my life. It would have been easier to climb Mt Everest."*

Bentall also developed akathisia – an extremely unpleasant sensation of inner restlessness, and an inability to sit still:

*"It was accompanied by a feeling that I couldn't do anything, which is really distressing. I felt profoundly depressed. They tried to persuade me to do these cognitive tests on the computer and I just started crying."*

Bentall's conclusion mirrors others who increasingly question the validity of research involving mind-altering drugs:

*"The experiment completely failed, because first, it's absolutely mind-bogglingly obvious to anybody after an hour whether or not they are taking an antipsychotic or a placebo - the side effects are so marked. There is no such thing as a placebo antipsychotic in that sense."*

These descriptive excerpts give a unique insight into the world experienced by many a patient but whose similar experience is rarely acknowledged or acted upon yet they resonate with what many patients have and are experiencing as we shall see.

## CHLORPROMAZINE IN USE

Heinz Lehmann, a German born Canadian, was a major force in the USA and published the first article in English along with G. E. Hanrahan (1954) promoting Chlorpromazine's usefulness in psychiatry:

*"The aim is to produce a state of motor retardation, emotional indifference, and somnolence, and the dose must be increased accordingly as tolerance develops. [...] The patients under treatment display a lack of spontaneous interest in their environment...they tend to remain silent and immobile when left alone and to reply to questions in a slow monotone...Some patients dislike their treatment and complain of their drowsiness and weakness. Some say they feel 'washed out,' as after an exhausting illness, a complaint which is indeed in keeping with their appearance"*<sup>38</sup>

Initially the psychiatrists saw chlorpromazine's effects in the same way as Lehmann with similar descriptions being used to characterize people on these drugs. Philadelphia psychiatrist N. W. Winkelman Jr. wrote that the drug transformed patients:

*"Who had been severely agitated, anxious and belligerent became immobile, wax like, quiet, relaxed and emotionally indifferent."*<sup>39</sup>

Another psychiatrist, Irvin Cohen stated:

*"Apathy, lack of initiative and loss of interest in surroundings are a common response in patients."*<sup>40</sup>

Along with these descriptions of people's emotional indifference and physical tranquility came the realization that these effects coincided with other Parkinson like symptoms leading to the speculation that Parkinsonism was perhaps an antagonist to schizophrenia. It was discussed whether such symptoms should deliberately be introduced and a meeting was arranged to discuss this by Smith, Kline and French (1955). About 100 psychiatrists including Lehmann met discussing in detail this phenomenon and one of the psychiatrists, George Brooks from Vermont State Hospital said:

*"We have begun to feel that quite frequently the greatest improvement coincided with the development of these [Parkinsonism] symptoms"*<sup>41</sup>

Another psychiatrist Hyman Pleasure reported,

*"Probably two thirds of our patients showed some degree of Parkinson-like symptoms."*<sup>42</sup>

And yet another Fritz Freyhan said,

*"[Chlorpromazine can] metamorphose a highly mobile, flighty manic into a static, slow/motion shuffler."*<sup>43</sup>

Contrary to today chlorpromazine and other similar drugs were **not** perceived as having anti-psychotic abilities. Instead, they were compared to lobotomy and their major function was to make patients easier to manage within the asylums which were overcrowded and functioned on inadequate budgets. Patients who previously were rendered manageable by electroshock or lobotomy which had reduced them to a

childlike state were seen in a kindlier light by staff and treated better. The same occurred when patients were quieted by chlorpromazine:

*"Chlorpromazine [has] produced a decrease in brutality in mental hospitals which was not achievable by any system of supervision or control of personnel... Many patients, for example, when they develop a central ganglionic or Parkinsonian syndrome become more 'sick' and thus arouse the sympathies of those taking care of them instead of arousing anger and hostility. The patients in consequence, receive better care rather than worse."* – said Anthony Sainz of Marcy State Hospital in New York.<sup>44</sup>

This drug by not being perceived as anti-psychotic meant that it was important for psychiatry to stress that it did not remove psychotic symptoms. For example Joel Elkes, England, wrote in 1954:

*"It is important to stress that in no case was the content of the psychosis changed... The schizophrenic and paraphrenic patients continued to be subject to delusions and hallucinations though they appeared to be less disturbed by them."*<sup>45</sup>

Lehmann and Hanrahan too were aware that chlorpromazine was suppressing their patients without affecting the delusions saying in 1954:

*"We have not observed a direct influence of the drug on delusional symptoms or hallucinatory phenomenon."* Later in 1955 Lehmann published his second article and in it he referred to the lobotomy like effects of chlorpromazine saying, *"Many patients dislike the 'empty feeling' resulting from the reduction of drive and spontaneity which is apparently one of the most characteristic effects of this substance"* and *"In management of pain in terminal cancer cases, chlorpromazine may prove to be a pharmacological substitute for lobotomy."*<sup>46</sup>

In Britain, Anton-Stephens called the lobotomy-like effect of chlorpromazine *"psychic indifference"* and throughout the early 1950s there are referrals to the lobotomy-like effects in the scientific literature but there were rapidly fewer and fewer and by 1960 this frontal lobe deactivation syndrome was actively denied. One of the major reasons for this change appears to be the role of the pharmaceutical industry.

The American Medical Association (AMA) was the medical watchdog requiring that the drugs proved themselves as beneficial before getting their stamp of approval and was independent of the pharmaceutical industry. But in 1951 the situation changed as prior to that very few drugs required a prescription. A new amendment was passed expanding the list of drugs requiring a doctor's signature, the purpose being to protect the public so that only the safest drugs were available. With this amendment the doctor's role changed in the eyes of the public but, so did their relationship with the pharmaceutical resulting in them becoming the doctor's closest ally. This had a profound effect on AMA in that their previous critical stance towards the medical industry disappeared as did their requirements that pharmaceutical industries provide proof of advertising claims coinciding with a massive increase in advertising revenue through AMA's journals. Ten years later 1961, Estes Kefauver after a two year investigation into the practices of the pharmaceutical industry could report how their marketing altered what doctors and the general public were reading regarding exaggerated benefits of drugs and glossed over risks through advertising. Scientific literature was not free from corruption either in that research critical of drugs rarely got printed and the amount of scientific articles ghost written by the pharmaceutical

industries was extensive. Likewise the popular press was given lucrative incentives to publish articles mentioning drugs in a positive light.<sup>47</sup> One can draw parallels between then and now in that this problematic situation continues as described by Peter Gøtzsche prof., overlæge, dr. med, of the Nordiske Cochrane Center when discussing the pharmaceutical industries fraudulent research and doctors bought out by the industry<sup>48</sup>, and indeed the recently published **Bad Pharma** by Ben Goldacre.

However what Kefauver also shows was that doctors and the public opinion about drugs were largely being formed by the drug industry and this factor played a critical role in refabricating the way psychiatric drugs worked. This can be seen by Smith Kline makers of Chlorpromazine who in 1954 launched their national US TV show called **The March of Medicine** and established a task force whose job was to coach, among others, psychiatrists on what to say about psychiatric drugs and perhaps more significantly what not to say. E.g., comments on chemical lobotomies and encephalitis lethargica were not to be mentioned. Instead psychiatrists were to talk about the statistics compiled by Smith Kline which showed money would be saved, the number of staff in asylums would be reduced due to patient improvement and in theory discharged, in other words the story many had dreamed of. TIME [Magazine] shortly after the launch of the TV show before the campaign had really taken hold, wrote an article **Wonder Drug of 1954?**

*"After a few doses, says Dr. Charles Wesler Scull of Smith, Kline & French, patients who were formerly violent or withdrawn lie "molded to the bed." When a doctor enters the room, they sit up and talk sense with him, perhaps for the first time in months. There is no thought that chlorpromazine is any cure for mental illness, but it can have great value if it relaxes patients and makes them accessible to treatment. [...] It is, says Dr. Scull, as though the patients said, "I know there's something disturbing me, but I couldn't care less.""*<sup>49</sup>

However the efficacy of the task force was noticeable, chlorpromazine was mentioned more than ten times in the New York Times and hailed as *"one of the most significant advances in the history of psychiatric therapy."*<sup>50</sup> None of the side effects such as lethargy or Parkinson's symptoms was mentioned in any of these articles and after a year the New York Times medical writer actively denied that patients experienced lethargy.

*"Patients do not develop the lethargy that follows the use of barbiturates...there is no doubt of the effectiveness of these new drugs in either curing or making hitherto unreachable patients amenable to therapy."*<sup>51</sup>

Likewise when chlorpromazine first came onto the market it was competing against lobotomy still seen to be a good treatment and so Winkelman, Smith Kline and French's leading investigator initially reported that the way chlorpromazine worked was *"The drug produced an effect similar to frontal lobotomy,"* and that it made the patients *"immobile," "waxlike,"* and *"emotionally indifferent."*<sup>52</sup> Yet three years later Winkelman in a large study involving 1090 patients, no mention of lobotomy like effects or motor dysfunctions were described, indeed the opposite was claimed in that he had *"not seen a full-blown case of Parkinsonism."* With only two patients who *"[...] exhibited the characteristic facies [sic] and gait, but without the cog-wheel rigidity or any sign of tremor."*<sup>53</sup>

In 1963 the word anti-schizophrenic replaced major tranquilizer after the National Institute of Mental Health (NIMH) launched a major double-blind study evaluating outcomes of newly admitted patients over

a six week period with extraordinary results. Almost half improved so dramatically that they were described as being virtually normal, with the further conclusion that the drugs reduced apathy and improved motor movement resulting in the drugs now being pronounced as curative.

*"Almost all symptoms and manifestations characteristic of schizophrenic psychoses improved with drug therapy, suggesting that the phenothiazines should be regarded as 'antischizophrenic' in the broad sense. In fact, it is questionable whether the term 'tranquilizer' should be retained."*

Thus from this other perspective, this contesting historical narrative shows that within a ten year period from when neuroleptics first entered into the psychiatric arena they experienced a remarkable transformation. They morphed from being viewed as a chemical lobotomy making the patients lethargic, emotionally indifferent and not reducing psychotic features, into the opposite, something governments, society and psychiatry dreamed of, aided by the pharmaceutical industry.

Biological psychiatry gathered momentum as it was discovered that the drugs worked by blocking dopamine receptors in the brain leading to the hypothesis that schizophrenia was caused by too much dopamine activity. This led to the birth of the chemical imbalance theory which 50 years later is still largely the story that is told, despite a lack of evidence.

One of the first to research this was Malcolm Bowers (Yale 1974) who studied dopamine metabolites in un-medicated 'Schizophrenics'. He found no evidence for abnormal levels of dopamine, however he did find abnormal levels in medicated 'schizophrenics' clearly indicating the brains attempt to compensate for the induced imbalance. Even the pharmaceutical industry admits their lack of evidence<sup>A</sup> yet that has not deterred the scale of drugging that those defined as mentally ill are exposed to.

There is, however, strong evidence convincingly demonstrated in **Anatomy of an Epidemic** (2010) by Robert Whitaker that the antipsychotics do in fact create chronicity, brain damage, and cause effects usually attributed to the symptoms of schizophrenia itself. Harrow's long term study, one of the few of its

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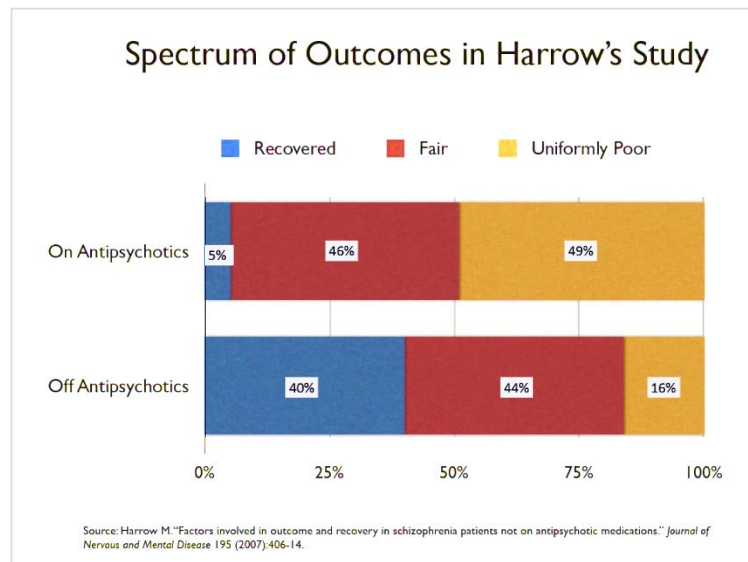
<sup>A</sup> Example: Risperdal taken from their website 2008. "The symptoms of schizophrenia are thought to be caused by chemical imbalances in the brain (either too high or too low). **Although it is unclear exactly how RISPERDAL works, it seems to help balance the chemicals in the brain.**"

Example: Risperdal taken from their website 2013. The symptoms of Bipolar I Disorder and schizophrenia are thought to be caused by chemical imbalances in the brain. **Although it is unclear exactly how RISPERDAL® CONSTA® works, it seems to help balance the chemicals in the brain.**

Example: Abilify taken from their website 2013. Many scientists believe that when the levels of these neurotransmitters aren't quite right, it may result in the symptoms of Schizophrenia [or depression or bipolar or irritability with autistic disorder] **The exact way ABILIFY [...] works is unknown. It is thought that ABILIFY may work by affecting the activity of some brain chemicals — adjusting dopamine, instead of completely blocking it, and adjusting serotonin.**

(Text emphasized by me) **Note the spread of antipsychotic medication to other diagnoses.**

types in the outcomes literature, followed a large group of patients on and off their medications and shows that people on antipsychotics have worse long term outcomes than those not taking antipsychotics.



This calls into question the established psychiatric truth that schizophrenia needs to be treated with long term/lifetime antipsychotics and supports the evidence that antipsychotics worsen global outcomes<sup>A</sup> for those diagnosed schizophrenic. It is difficult to find systems of care which advocate less or no drugs is better; however an good example of such a system is Open Dialog in Western Lapland. They adopted such a system of care in 1992 and have one of the best outcomes in the world in terms of full recovery supporting Harrow's results.

This counter history supports postpsychiatry's critic of, and desire to move beyond the current technological paradigm. It is also these psychiatrists who are prepared to acknowledge that the current psychiatric treatment paradigm is in a crisis as expressed by 29 psychiatrists who in a joint article stated:

*"Over-reliance on psychopharmacology as the primary response to serious mental illness created the conditions for a blindness towards the serious adverse effects of some psychiatric drugs, and for a shameful collusion with the pharmaceutical industry's marketing campaign that sold the illusion of major innovations in antipsychotic drugs."*<sup>54</sup>

Thus a clash between modernism and postmodernism appears to be unfolding where academic psychiatry finds itself increasingly confronted between the meeting of the centered, modernistic, scientific and technological versus the decentered, postmodernistic fragmentation, with role jumbling, poly vocalization and discourse specific truths of postpsychiatry entering the arena. This can also be said of many who critic psychiatry however, psychiatry with its origins in the era of enlightenment appears to have trapped itself in its insistence on seeking a singular whole, by demanding of itself that its truth is to be found in the brains of its patients. A potential scientific truth perhaps, but as other historical narratives emerge the

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<sup>A</sup> For example in Denmark as in other countries the increasing numbers being placed on pensions due to mental health issues has been steadily increasing with each year, from 1999 27% of all new pensions were for psychiatric patients. In 2010 it was over 50%.

inability of psychiatry to produce the evidence demanded of its own modernistic enterprise is resulting in destabilization of self.

The contesting history on psychiatric medication hints that other discourses exist and by creating spaces for other voices, postpsychiatry recognizes that knowledge from a postmodern position is contingent on having multiple sites of production and that a variety of different perspectives must be brought to bear on the interpretation of mental distress. The right of the service user to define their own reality is paramount, which will include acknowledging their subjective experience of taking psychotropic drugs, something that has been absent in the officially endorsed psychiatric literature so far. But before introducing the voices of the seven interviewees, I will introduce postpsychiatry and some of the other theorists who underpin this thesis.

## THEORETICAL INTRODUCTION

Antipsychiatry, Critical Psychiatry and Postpsychiatry all have in common a criticism of orthodox psychiatric praxis yet they take different approaches. Jacques Lacan is seen as an early influence to antipsychiatry, particularly in the UK because he challenged psychoanalysis and encouraged a reexamination of its concepts along with an emphasis on psychosis as meaningful, something that was a mark of antipsychiatry.

### ANTIPSYCHIATRY

ANTIPSYCHIATRY arose in the 1960s and 70s in a time when the full horrors of the eugenics movement and the psychiatrists' roles in those events had been exposed after WW II, the ongoing treatments such as lobotomies and electroshock and later the effects of medication. As a term antipsychiatry was first coined by David Cooper in 1967, yet those who in the public eye are often described as the epitomes of antipsychiatry, R. D. Laing and Szasz, have never acknowledged the term. So though antipsychiatry is still a term that is referred to, more often in a derogatory manner than as a valid criticism, it is more of an umbrella term representing an eclectic group who had a critique of psychiatry in common. Indeed it is only recently Szasz died, yet he has written scathing analyses of psychiatric praxis right up until his death, long after antipsychiatry as a concept has been relegated to the history books. As recently as 2008 Szasz reiterated his dislike of the term antipsychiatry saying it is a "[...] *catchall term used to delegitimize and dismiss critics of psychiatric fraud and force by labeling them 'antipsychiatrists'*"<sup>55</sup>.

During this period a variety of seminal works were written, Szasz and **'The Myth of Mental Illness'** (1961) Goffman **Asylums** (1961) Foucault and **Madness and Civilization'** (1961)<sup>A</sup> and R. D. Laing with **Sanity, Madness and the Family** (1964). All look at madness from different perspectives. Others like David Smail also considered part of the antipsychiatry movement writes today about the embodied nature of the individual, critiquing the present day belief that we can heal ourselves through therapeutic help which he states is more wishful thinking reflected in societies' need to ensure consumer capitalism succeeds. This

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<sup>A</sup> Original title was *Madness and Unreason: A History of Madness in the Classical Age*, but mostly known as simply the *History of Madness*. It is in the English-speaking world known as, *Madness and Civilization*.

focus on consumerism is an aspect that is in alignment with much of present day critical psychiatry/psychology thinking.

Antipsychiatry lost ground when psychiatry unable to successfully counteract antipsychiatry's critique chose to restructure focusing on a biogenetic biomedical approach which proved as noted earlier, to be highly successful.

Considering how radical and damaging antipsychiatric critique was, one can wonder how it became undermined. Psychologist Peter Sedgwick took a different standpoint by seemingly to pick from both sides rather than just viewing psychiatry as all bad. He suggested on the one hand more and better psychiatric hospitals and more beds and nurses, while at the same time supporting antipsychiatry's desire to reject and undermine the credibility of psychiatry's reductionist approach to mental distress. He took the stance that *all* illnesses not just mental illness existed, but as social construction. So he was not denying the fact that extreme states defined as mental illnesses existed but he viewed them as he did other illnesses, as deviations from an established norm. Thus he differed by seeing that if there was no illness construct there would be no possibility of getting help from mental health services which is why he saw that personal rights could not be separated from social freedoms.

*"It may prove possible to reduce the distance between psychiatry and other streams of medicine [...] not by annexing psychopathology to the technical instrumentation of the natural sciences but by revealing the character of all illness and disease, health and treatment, as social constructions. For social constructions they most certainly are." 56*

From his perspective, the dualistic, absolutist approach of antipsychiatry and in particular Szasz, was therefore doomed, simply because distress existed as a socially constructed entity, was multifaceted, served a purpose and would not go away by saying it did not exist. Antipsychiatry did not provide alternatives for help on a scale to cover the demand, which is why Sedgwick advocated for not more of the same but a better psychiatric system.

Sedgwick can therefore be said to be closer in thinking to Foucault and postpsychiatry though postpsychiatry would not equate somatic illnesses with mental illness in the same light as Sedgwick, Mol or Jensen.

## CRITICAL PSYCHIATRY AND POSTPSYCHIATRY

CRITICAL PSYCHIATRY and postpsychiatry have come about in what could arguably be described as the heyday of traditional psychiatry's restructuring, a period when psychiatry convinced of its biological explanations and medical solutions, went largely unquestioned. CPN became official in 1999 due to concerns over the proposed increase in judicial psychiatric coercive powers including forced treatment in the community. Both critical and postpsychiatry have much in common and can perhaps best be viewed as existing along a continuum where postpsychiatry moves beyond critical psychiatry. Thus postpsychiatry shares much of the ethos of critical psychiatry whereas the opposite is not necessarily true.

CRITICAL PSYCHIATRY'S major focus is critiquing the biological emphasis of modern psychiatry's research, which helps create a false impression that the credibility regarding evidence for justifying medication, is sound. Joanna Moncrieff author of **'The Myth of the Chemical Cure'** goes into great depth on this issue

where she exposes the traditional view that psychiatric drugs help as fraud and that if the real nature of psychiatric drugs were to be acknowledged it would lead to a more democratic psychiatry. Duncan Double, editor of the book **Critical Psychiatry – The Limits of Madness** a tribute to a book of the same title but written 30 years earlier by David Ingleby, deliberately echoes the original. He highlights the fact that “*The issues of critical psychiatry are therefore not new.*” and “*The modern version of critical psychiatry [...] is 'post anti-psychiatry,' [...] when it has had time to reflect on the impact of anti-psychiatry.*” In other words the present day critique of psychiatry has its roots in the antipsychiatry movement and represents a progression or a further unfolding of what was started in the 60s and 70s. With its focus on the validity of medication, authors such as Robert Whitaker’s whose analysis of long-term psychiatric drug use appears to indicate that they may actually be more harmful, plays a significant role. So just as psychiatry uses science to reinforce their belief in the medical model of psychiatry, critical psychiatry uses science to question the validity of the medical model and reemphasize the more metaphysical aspects of distress such as meaning and understanding. Thus both critical and postpsychiatry view the declining interest in hermeneutics as problematic, as closing the door to interpretation and meaning increasingly alienates those it purports to help. This concern is shared by those service users who are not prepared to define themselves and their problems through the language of psychopathology.

POSTPSYCHIATRY has gone a step farther, for where critical psychiatry covers a broad range of opinions and is concerned with how much can be achieved *within* psychiatry; postpsychiatry is linked to postmodernism and does *not* seek to find solutions within psychiatry. Instead they advocate we should be moving beyond psychiatry, encouraging an acceptance that not all human problems can be grasped in a modernist technological manner and having “the *imagination* to think what a post-technological or a postpsychiatry would look like.”<sup>57</sup>

Patrick Bracken and Philip Thomas are the main actors in postpsychiatry, viewing psychiatry arising as a modern enterprise based on the enlightenment period as they pictured here

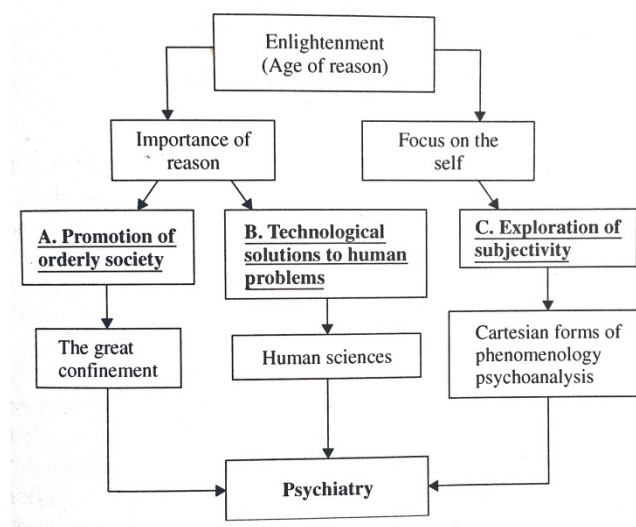


Fig 1 from Postpsychiatry, Bracken and Thomas p. 7

Though they support the criticisms voiced by critical psychiatry they specifically advocate for the deprofessionalism and demedicalisation of psychiatry and by placing mental distress firmly in a social context, advocate that diagnoses is a matter of negotiation between client and the psychiatrist.

In particular they view academic psychiatry as being guided “by a profound ideological commitment to what is known as reductionism.”<sup>58</sup>

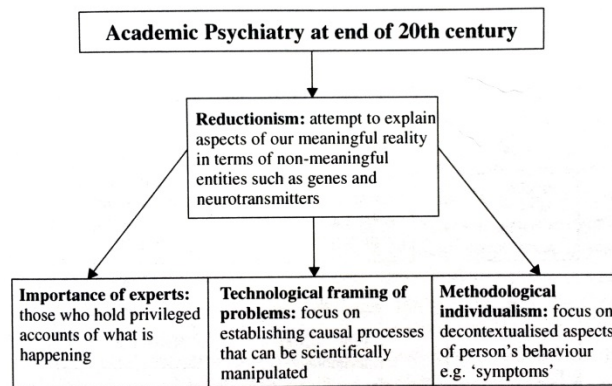


Fig 2 from Postpsychiatry, Bracken and Thomas p.15

They also question the paradigm of recovery which in psychiatry is often viewed from a perspective of a reduction or lessening of intensity of symptoms. Instead they promote supporting that it is the person herself who defines his recovery.

Postpsychiatry has commonalities with antipsychiatry, however Bracken & Thomas want to avoid the polarization that was created by the antagonism that existed between psychiatry and anti-psychiatry<sup>59</sup>. In other words they are hoping for dialogue, something antipsychiatry expressed little interest in, or more likely saw as unimportant in that they, like psychiatry, believed that there was a correct way to frame madness. Postpsychiatry does not believe there is a correct way to frame madness instead, it views its purpose as opening up spaces where other perspectives can assume a valid role, significantly it argues for the voices of survivors and (ex)users of psychiatry to assume center stage. Bracken & Thomas advocate a joining of professional expertise with that of the laypersons experience and give such a prominent role to service users that according to some critics of postpsychiatry “psychiatrists appear mainly sidelined”<sup>60</sup>. So though anti/critical/post psychiatry share elements with each other the advocacy of a true joining of those who use and have used services is unique to CPN and in particular postpsychiatry.

Postpsychiatry draws on the critique of the modern mind by in particular Foucault, Martin Heidegger and Ludwig Wittgenstein working towards a hermeneutics of distress. Bracken & Thomas’s focus is on power and moving beyond a Cartesian type of phenomenology as defined by Karl Jaspers inspired by Renee Descartes and Edmund Husserl, a type which continues to infuse modern day psychiatry. Thus Bracken & Thomas are concerned with the way psychiatry sees people and the problems they have as expressed in psychiatry’s Cartesian approach and the power of the ‘gaze’ as described by Foucault. This approach allows psychiatry to disempower by separating the body from the context of human experiences and the potentiality of meaning making. This is because Jaspers approach concerns itself with identifying

psychiatric symptoms by separating the *form* of the symptom from the *content* opening up for the power of the gaze. He saw the *forms* of psychopathology as being universal and occurring inside the individual, whereas the *content* was socially and culturally mediated context and of secondary value, something that is evident in psychiatry's medical model of madness.

Heidegger therefore plays a significant role introducing the concept of meaning as a non-scientific issue through his two main areas of inquiry, the ontological and the ontic. To use Bracken & Thomas's metaphor; Jasper's view of human psychology is like an avocado, the pip is where universal processes occur which are context independent and Jaspers scientific psychopathology comes about through trying to grasp *the nature* of the pip. Therefore, to gain access to the pip so as to expose the pip to a true scientific gaze, the flesh around the pip must be removed which here represents the world of context and meaning and where the individual's psychology resides. A hermeneutic phenomenology as represented by Heidegger is likened to an onion with no central core, just layers representing there is no human psychology without context.

Wittgenstein introduces the concept of the mind and language and the fact that according to him there is a one to one relationship between the person and the world they are relating to through words. I.e. he regards language as a social and human phenomenon. This he says can be thought of as rules in the terms of games, where the rules are flexible to account for changing times and different cultures but, that language is about its place in human activities and lived life. He addresses the issue that what we feel/our inner world, is different from the agreed upon rules for engaging with the outside world, for though we agree upon and describe such things as a feeling of happiness it will remain uniquely our own experience and we will never know if the happiness I feel is the same as the next person's. This has, says Bracken & Thomas, tremendous consequences for psychiatry, for when psychiatry imposes a positivistic reductionism of lived life with stories of trauma and loss, e.g. rating scales such as the Hamilton scale which attempts to measure sadness even though sadness is an unmeasurable entity, psychiatry *acts* as if it was a measurable entity. However, because the mind, our inner worlds is unmeasurable and inseparably linked to context emotions, values, and beliefs, they exist as if they were physical entities, yet remain outside the realm of physicality. What Wittgenstein does is show that we cannot discuss our inner knowledge of the mind in a Cartesian manner for what we say about our inner mind is intimately connected to our outside world of cultural social and historical contexts and makes us according to Bracken & Thomas "*above all else embodied social and cultural beings*"<sup>61</sup>

Accordingly, postpsychiatry has, by questioning the validity of the biomedical model and the reductionism of modern psychiatry and engaging fully with the user movements, created three major goals.

1. The importance of contexts, in other words political, social and cultural contexts should be center stage in understanding mental distress. A context centered approach allows for non-cartesian models of mind as exemplified by Wittgenstein and Heidegger with an emphasis on the term hermeneutic which here means priority is given to meaning and interpretation.
2. Ethical rather than technological orientation meaning a move away from the belief that science guides clinical practice in psychiatry to acknowledging that psychiatry is primarily concerned with beliefs, moods and behaviors and that values and assumptions regarding these issues is what underpins psychiatric classifications. If this is ignored, dangers arise as can be seen by the problematic

encounters with those diagnosed schizophrenic or people suffering distress from other cultural backgrounds.

3. Rethinking the politics of coercion. Many who use psychiatric services question the medical model of psychiatry and are outraged that this forms the basis for force. Postpsychiatry wishes to relinquish the right to detain and/or force treat the mentally distressed and advocate a principle of reciprocity meaning any legislation allowing force has to have safeguards such as advance directives and advocacy.

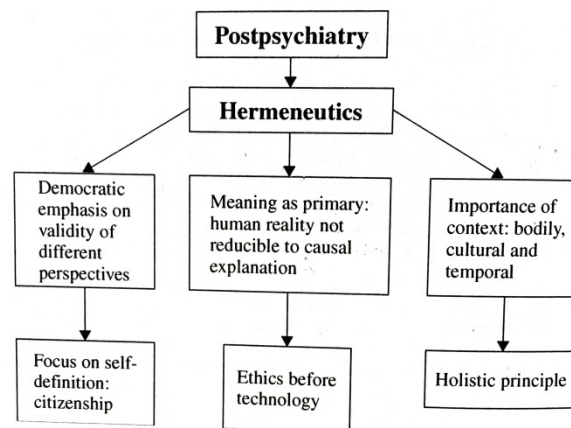


Fig 3 from Postpsychiatry, Bracken and Thomas p.16

These are goals which resonate with among others the HVN.

## THE HEARING VOICES NETWORK

The HVN which has existed for more than 20 years in the UK, eight years in Denmark, was inspired by the innovative research by professor Marius Romme and Dr. Sandra Escher, who because of their research advocated a radical new approach and a profound shift in perspective on the symptoms traditionally associated with schizophrenia; hearing voices. These symptoms have traditionally been viewed as symptomatic of a biological disease with a genetic etiology, however they established that the voices were meaningful and make sense when viewed in conjunction with the traumatic life events that provoked them<sup>62</sup>. They and others<sup>63</sup> show that at least 75% who hear voices have had some traumatic experience connected to their voices.

HVN is an influential grassroots movement which openly critiques traditional psychiatry's relational roles of 'passive, recipient patient' and 'dominant, expert clinician' and has instead created spaces where people across many disciplines can work together to gain a better understanding about those who hear voices, see visions, feel tactile sensations and other sensory experiences. The HVN has created a strong self-help tradition where people can meet in a safe place and share experiences, *"without the threat of censorship, loss of liberty or forced medication, a common feature of disclosure in traditional psychiatric settings."*<sup>64</sup> Likewise they have developed, researched and published their own methodologies, techniques and narratives as separate from psychiatry to help those who have problems with their voices, visions etc. One such book, **'Living with Voices'**, (2010) 50 anthologies from voice hearers from many different countries who have learned to live with their voices by accepting them, has highlighted several key themes:

- Voices are a survival strategy pointing at past and present problems often using the language of metaphors representing emotions split off from self and telling tales of often dreadful events while attacking yet protecting the person's identity.
- Trauma is a dominating theme ranging from sexual abuse, emotional neglect, physical abuse, bullying and it becomes clear that these events play a profound role in the development of alternative beliefs/experiences.
- Recovery is not about getting rid of the voices but about understanding their message(s) and changing the relationship so that the voices may become helpful and cease to be so damaging.
- Interestingly, another theme that came out of the 50 anthologies was that recovery had only become possible outside of psychiatry.

Thus with the Hearing Voices Movement, madness is placed in a context where it can become accessible as understandable which challenges those who view these experiences as irrational, or as symptoms of an underlying biological phenomenon. Therefore, depending from which perspective one approaches symptoms typically ascribed to schizophrenia, different realities can appear or disappear. Which is why Annmarie Mol and her perspective of multiple realities in practice becomes interesting though she in her book **'The Body Multiple'** focuses on atherosclerosis, which exists in a physical form, contrary to the phenomenon of mental distress which as a physical entity is contested. For though psychiatry can identify focus objects in schizophrenia, its inability to convincingly link them to schizophrenia means that they must continually address these inconstancies, resulting in their interrelations becoming opaque, contested, ideological etc.

However Mol states, *"It possible to refrain from understanding objects as the central points of focus of different people's perspectives"*<sup>65</sup> and by doing this she is pointing out that it is possible to understand people as objects manipulated in practices. Thus if we foreground the practices rather than bracketing them as is the tendency, there is no longer a single passive object (patient or medicine or illness) in the middle waiting to be seen, instead a *"seemingly endless series of perspectives"*<sup>66</sup> come into being and in a similar vein *"objects come into being - and disappear - with the practices in which they are manipulated. And since the object of the manipulation tends to differ from one practice to another, reality multiplies."*<sup>67</sup> Thus there is a move away from the epistemological approach to knowledge which looks for the preconditions for the acquisition of true knowledge and instead, focuses on understanding knowledge as manipulation, rather than of reference. Universal truth ceases to be important, instead the question becomes, how are objects handled in practice?

Psychiatric drugs which are the object from which this thesis grows, are filled with controversy engendering powerful emotions yet, the realities are created by the practices surrounding them as well as drugs themselves. This reflects the power struggle that is implicit when questioning the medical domain of psychiatry and which is again reflected in the readily accessible but filtered knowledge about these drugs. By giving voice to those subjected to psychiatric medication some of these discrepancies that exist between psychiatry's experience and theirs will be reflected here including the contexts surrounding them.

## INTRODUCTION TO THE SEVEN INTERVIEWEES

I wish to give the seven interviewees, five men: Lou, Ben, Zac, Joe, Leo and two women Mia and Pat, voice in the current discourse of psychiatry. I am aware that I cannot possibly express the richness of seven interviews in the space of this thesis yet, I believe their voices will still be heard and their experiences with psychiatric medication and the context surrounding the medicalization of them will be clearly expressed.

There are a myriad of ways I could have chosen to group or not, my seven interviewees, however, I have chosen to divide my interviewees into three groups. **'Accept medication'**, **'doubt medication'**, and **'off medication'**, in order to address, from a postpsychiatric perspective, the discrepancies between service users and psychiatry's experience of psychiatric drugs. I will also introduce my interviewees in more depth as I analyze their dialogue within these groups but I wish to start out in a more general manner looking at what they all appear to have in common, before narrowing down into the three groups and ending with a generalized focus on trauma.

All seven have heard voices, though some more than others, all have been given the diagnosis of schizophrenia and though some reject that label today, that is never the less the lens through which they have been viewed. In terms of the space of psychiatry, all have been admitted to the psychiatric hospital, including being on the locked ward at some point in time and all have had contact with psychiatry in its various forms over a period of many years. All have been, or are on state support, in other words been so affected that they have been unable to support themselves and live(d) off benefits. Psychiatric drugs have played a significant role with effects which profoundly affect or affected their lives as will be revealed in more detail and all have tried many different medications and combinations thereof.

My interviews were done using an unstructured, naturalistic approach inspired by J.M. Johnson as this among other things allowed my interviewees to describe in their own words their experiences and understandings of medication as well as to digress to areas that are of importance in their meaning structure. The technical idiom of psychiatry has tended to be a monologue of reason about madness, which is what postpsychiatry wishes to end, and in so trying, opens up spaces to multiple realities such as described by Mol and that of the HVN. This means when analyzing the texts, context cannot be ignored and one of the aspects that they all shared was trauma. Research on the links between trauma and child abuse, particularly sexual abuse and the later risk for psychosis/diagnosis of schizophrenia has been shown to exist in all large-scale studies<sup>68</sup>. This is also the case here as all report difficult and traumatic childhoods. Five of the seven have been exposed to sexual abuse, one to psychological abuse and bullying and one the traumatic event(s) were not touched upon directly in the interview but referred to obliquely several times over the course of the interview. This is significant which is why I will end by looking at trauma in more depth as stories of abuse are extremely common in psychiatry, yet regularly rendered irrelevant, ignored or indeed perceived as delusional.

But now I want to introduce in this next section, my interviewees subjective, medical knowledge including the contexts framing and surrounding these practices.

# CONTEXT OF MEDICINE

## ACCEPT MEDICATION

**Lou, Ben and Zac**, three current users of psychiatry who view medication as positive. I met Ben and Lou at the World Hearing Voices Congress in The UK accompanied by **Kat** a worker. Ben is on a locked ward in forensic psychiatry and Lou is now in a supported community placement. Lou talked quite a bit about his violent crime which is why he has been in psychiatric care for many years. Kat was present during parts of the interview participating actively with regards to Ben and his dissociation which resulted in his interview terminating early (see *trauma section*). I interviewed Zac in Denmark and his connection to psychiatry is through the psychiatric center. The settings were very different in that the one joint interview was at a dynamic international conference where we sat together around a table where each took turns in talking and the other interview was in the quiet of his home. All three live off state subsidies.

## Lou

Lou initiates by describing a normative reason for taking medication; they stop him from being mad:

**Lou** I take them because they sort of stabilize my mind and they bring me down from madness and stuff, they bring me down from insanity. When I first went onto Clozaril it didn't do very much for me [...] it takes time to acclimatize the drug inside of me but the Clozaril it's brought me down from the madness:

*How does it do that for you? How's that work for you?*

**Lou** it sort of brings me into; if I didn't have it I would be very, very insanely ill

*If you were to describe it, how would that... how would that be?*

**Lou** umm shooting up in the air dancing around insanely, talking to voices that aren't there I mean...

*Are you sort of very happy or excited?*

**Lou** I get over happy. It actually brings me down because I get over happy but the happiness is an insane sort of happiness it's umm hard, too hard to explain but it's a very insane sort of frame of mind

He describes an emotional stabilizing effect which he interprets as a reduction of insanity which caused him to talk to the voices yet that is not the real reason he takes medication:

*The effect is it working on your emotions or just on your sense of...*

**Lou** it works umm... I have to have it because I, I... I used I, I, I at times, years ago when I was completely sort of schizophrenically crazy I beat someone up in the street and I ran down the street laughing and dancing

Having committed a violent crime for which he feels guilt and remorse he views medication as the price he must pay and has to have something I felt he shared with Ben when he said:

**Lou** me and Ben the drugs, we have to have them, the meds we have to have them, we both need it even though it might be going against the grain to just having a nice time and going a bit mad once in a while but...

Though he views medication as something he has to have he also views it as help in that his emotions including over happiness are dampened. This is perhaps why he does not question how much medication he gets, he just takes them as prescribed:

**Lou** how much do I get? I take 2 in the morning 2 in the afternoon evening and then 3 at night [...] I am not sure how many mills [mg] they are, all I know they are little yellow pills and they keep me from going mad! [...] I take them as the doctor prescribes.

From a legal point of view Lou's crime is technically not a crime, by reason of insanity and so psychiatry must act upon this embodied illness entity, the culprit of this violent crime, by medicalizing it. This theory is on the surface to be applauded, for if the person is not responsible then they cannot be held accountable. Yet, by not being accountable it means that the person must be devoid of reason and lack insight which leads to a notion of unpredictability. This instills fear, something that is a common reaction from society and psychiatry when it comes to people diagnosed as schizophrenic. This in turn feeds into stereotyping and discrimination. Szasz has been particularly vocal on this issue, rejecting the insanity plea stating that fear of the mad and society's acceptance of the psychiatrist's role in protecting them from the dangers of the madman lay the ground for a well-camouflaged trap for condoned coercive paternalism. This is he says is legitimized because it "*rests on a fiction that "caring coercion" benefits the coerced, not society.*"<sup>69</sup>

Though there are a myriad of reasons for violence occurring regardless of whether one has a diagnosis or not, one of the consequences for allowing the insanity plea has been the justification for what one would define as state sanctioned violence in the form of psychiatric laws allowing forced drug treatment, ECT and detention. However these laws are not just for those who commit crimes, but also for those who reject treatment. Bracken & Thomas believe "*there needs to be a substantial weakening of the link between treatment and coercion*"<sup>70</sup> as only then can there be a genuine collaboration between psychiatric (ex)users and psychiatry, not to mention complying with UN anti-torture policies.

However, they go further than just the obvious coercive power. The power of the dehumanizing gaze separating the person from his context and lived life, reducing him to a pathologized entity based on psychiatry's Cartesian phenomenology, has profound consequences. E.g. the gaze of psychiatry on hearing voices from this perspective will regard the *form* of the voices that discuss the person as a 'third person auditory hallucination' and stop there, rather than look at the *content* of the voices, thereby gaining access to context and meaning. Or, as in Lou's case, the gaze views him as schizophrenic, embodying an internal pathology from which his act of violence arises and therefore the circumstances surrounding Lou's act of violence are seen as secondary and of little relevance, denying him the opportunity for context and meaning. This strips Lou of his power as a person as the inequality of the psychiatric system; that has the power to detain and treat, something that lurks beneath the surface for all who enter the psychiatric

system as a service user, has deemed him devoid of reason and the circumstances surrounding his act of violence as meaningless. Because of this *"many users see their time in hospital as punishment."*<sup>71</sup> Though Lou does not say that directly it is precisely because he views medicine as something he has to have which is perhaps why replacing intoxicating substances, which he links to his act of violence, with psychiatric drugs and an illness paradigm has resulted in:

**Lou** [...]I've been clean now from drugs for the last..., coming on 14 years [...] basically all I can say is that I'm grateful to be on my meds today because I never want to revisit Mr happy violent man because it might make me Mr happy violence

Not so much because he has become well in the way psychiatry might be envisioning but more because the medicine is no fun compared to street drugs as he wistfully describes:

**Lou** I actually think in this country they should make the doctors pills, who are for the schizophrenic people, -they should make them so that they work well and also give them some fun.

*Do you feel your fun has disappeared with the clozapine?*

**Lou** Yes at times, but I think they should work well and they should give a bit of fun as well, and that would keep people off taking drugs wouldn't it in their schizophrenic conditions and stuff? If they made a pill that worked well controlling the hallucinations and stuff *and* was a fun thing to take then there would be hardly anyone in the schizophrenic community on the illegal drugs

Presented here, is a multitude of different realities, for from psychiatry's perspective their treatment of the embodied pathology ensures that Lou is unlikely to be violent again. From Lou's perspective he associates his substance abuse as playing a role, that he is ill, and that he had a reason at the time, "I thought he was a child abuser". However though Lou has been sexually abused and hearing voices is closely associated with that, statistically speaking it is drug and alcohol abuse that is linked to acts of violence and Lou was an extensive user.

**Lou** Then I started smoking dope when I was 12 then I started taking mushrooms at about 14 magic mushrooms and by 18 I was taking speed again knocking back everything ecstasy, speed, Coke, heroine, morphine, barbiturates, the whole lot.

His great pleasure, street drugs has now been replaced by non-pleasurable drugs and it is also clear he fully accepts his schizophrenic identity including the belief that violence is connected to the illness and that drugs are a necessity. He extrapolates that psychiatry could help schizophrenics in general not to be drug addicts and bad things happening, if psychiatry made the medicine pleasurable. Many, including Lou would say medicine is better than visiting Mr happy violent man and certainly violence has not been a part of his life for many years. However it makes me think of the whole issue of responsibility and the absolution of responsibility. It is clear each foregrounded facet has its own unique perspective and from my perspective externalizing violence and placing it into a socially constructed illness has far reaching consequences that go beyond Lou, it contributes to the stigma and stereotyping of those labeled schizophrenic in general.

## BEN

Ben whom I interviewed at the same time appears also to be subject to having an identity very much formed by the defining powers of psychiatry like that described by Lou.

When explaining why he takes medication, Ben initiates by listing his drugs and the illnesses they relate to

**Ben** My experience I'm, just to explain. I'm on Abilify which is, -obviously I'm psychotic-, I'm on carbamazepine, which is a mood stabilizer and citalopram which is an anti-depressant and I have been on psychiatric drugs since the beginning umm, start of the age of 16.

But like Lou there is also another story that hints at a different reason.

**Ben** The reason I started on the drugs [was] as I said, the voices, the things I was experiencing, the things I was seeing, the things I was hearing, some of the beliefs I was feeling, some of the things that was happening were quite..., the doctors said, they were quite concerned at one stage that I was developing a resistant kind of schizophrenia. There is a history of schizophrenia within the family, so obviously that's why they were very keen to put me on medication. [...] My mental health problems started a bit before the age 16 and they weren't very keen about putting me on medication below the age of 16. But as soon as I reached 16 and started to err, things started to get worse with my mental health, it was then they started to put me on medication and Prozac was the first mental health drug I was put on. That kind stabilized me, helped me feel a lot calmer, much more relaxed and my mood stabilized and became more settled as well, and then obviously, the next drug I was put on a bit later was obviously Risperdal, very low dose Risperdal and that helped with sort of well at one point I was actually voice free.

Ben has grown up in a family with a history of mental health problems so psychiatry has been a part of his childhood. However it almost appears from what he says that he has been destined to be a schizophrenic and psychiatry was waiting until he passed 16 to start medicating him and he has in his five years since starting on Prozac tried different antipsychotics as well as the mood stabilizer Carbamazepine. I am therefore in agreement when Whitaker states "*now this epidemic has spread to our children. Indeed, millions of children and adolescents are being groomed to be lifelong users of these drugs.*"<sup>72</sup> Referring here to the many children in the US who today are consuming antipsychotics and mood stabilizers primarily due to "an iatrogenic epidemic: 400,000 bipolar children arriving via the ADHD doorway, and at least another half million through the antidepressant doorway."<sup>73</sup>

The ability to determine whether an individual has committed a crime based on reason or madness has expanded as psychiatry's legitimacy, status and authority has grown. It requires specialized expertise to be able to see inside the individual founded in the medical gaze however today psychiatry is positing an increasing ability to be able to predict potential madness, to be expressed at a future time, lying dormant within a child.<sup>74</sup> Ben was under the gaze of psychiatry as a child, the question is are we dealing with a self-fulfilling prophecy, social inheritance or something else?

Interestingly Ben like Lou initiated by stating the reason for taking medication was because he was ill, aligning himself with the medical model yet, they both after this initial alignment proceeded to talk about what they really believed and what gave meaning. Here Ben states very clearly his opinion:

*So there's also something with the life story as well?*

**Ben** yeah! I believe very strongly about the life story. I believe very strongly in the fact that people's life experience and life stories and stuff and what people have been through in their life can have a major impact on what happens when they are older and stuff.

This clarity of expression reflects perhaps the influence of the HVN and Kat's active role in introducing them to these other realities and truths. So though neither are free to leave psychiatry they are being exposed to other ways of thinking which gives them access to acknowledging life stories, the possibility of meaning making and perhaps ultimately agency over self.

## ZAC

ZAC who has been in psychiatry since he was 18 has not had access to, or has not found it relevant to look at alternative ways of viewing his situation and though he is 'free' in that he lives independently, he has accepted the psychiatric illness paradigm and has formed his identity around it. Interestingly he, contrary to the other two, started by describing his symptoms and his suicidal thoughts as an 8 year old due to being sexually abused, rather than his medications and how they function for him. It became clear to me he attaches little credence to his life story as playing a role in his mental state yet from my position coming from the HVN it appears oddly out of place and glaring by the role it appears *not* to fill. Zac was the interviewee furthest from my position and closest to psychiatry's of all my interviewees and his interview also affected me emotionally in that I felt what I perceived to be his hopelessness. Though I had consciously made a decision not to try and 'influence' him by saying there was another possibility than an acceptance of a biological interpretation which seemed to fuel this sense of hopelessness, I was not entirely successful. This first became clear to me when I transcribed the interview as at the end of the interview I thought I had succeeded.

For example, when he described the effects of his medication I found myself thinking, "that is a dangerous cocktail he is on" and the symptoms he described are symptoms that I found alarming:

*Is that what you've been prescribed? Do you follow the doctors' orders?*

**Zac** Yeah, exactly, 300 mg [Effexor] a day but still I have depressions but not as bad as they would be. I started on antipsychotics here again I started on Risperdal and on Solian and erm... on Seroquel.

*Oh okay so you are on quite a number!*

**Zac** I started with them...

*Ah you started on them*

**Zac** ...and I tried different ones and they made me, like very like dizzy and stuff like that and finally we found Abilify so I'm taking 30 mg a day and they keep the top of; not the top of but a great deal of my psychotic experiences away. Then I take; I have Truxal as P.N. I'm very sensitive towards it so I take 50 mg of it and I get very, very dizzy and I have to sleep, it takes the anxiety away. I've developed strong anxiety attacks at night where I have involuntary movements of my body and err... I have cramps and... can't breathe, my heart beats very fast and I have pain in my arm and stuff like that

*Okay so you actually have the pain in your arms?*

**Zac** when I have anxiety and my extremities, my legs sometimes and my chest erm... terribly, really strong anxiety attacks and for that I use; -if they're not that bad I just hold on, if they are bad I take an Oxazepam and if there really bad I take Rivotril but erm... if I take medicine it has to be three days in a row at the most, tops if I have an attack the fourth day I just hold on no matter what, because I don't want to become addicted to the benzo's

*No no, so... When you say the cramps, do you attribute it to the anxiety? It's not side effects or something?*

**Zac** no no no no!

*No?*

**Zac** no

*No?*

**Zac** I go to bed and 40 min afterwards I wake up with anxiety

*Okay, yeah [pause] So, do you have many nightmares?*

I am in a dilemma. Because what he attributes to anxiety attacks I attribute to possible serious side effects, a situation which he describes as appearing approximately 40 minutes after taking his medication which wakes him up. Also it is most unusual to have an anxiety attack while sleeping. Zac takes two antipsychotics, one antidepressant, and two diazepam derivatives when needed however this combination of in particular antipsychotics and diazepam is not recommended by the Ministry of Health because of the risk of sudden death. This fear is what affects my dialogue with Zac as I question his insistence that it is anxiety attacks.

On another occasion when Zac is describing his experiences of paranoia I find myself interpreting.

**Zac** I smell things. That's actually one of the most common hallucinations I have. When I am without medication I build things up, very complex paranoia, and er, prosecution stories about PET hacking my computer and profiling me as a murderer things like that

*So you're portrayed as a murderer? [he told me he had experienced the murder of a very good friend]*

**Zac** Yeah, or Jesus or something like that. When I am medicated I just get this thing, this er..., small psychotic episodes. I get to smell things like rotting things like death and... er... excrement and things like that

[...]

*So when you say these smells and things, I'm just thinking of myself and other people I have heard, I relate it to my past. They are related in some way. Do you experience yours [like that]? Or is it out of the blue?*

**Zac** It is just out of the blue. [...] Most of the times I feel like I am a savior or I have to create balance in society and things like that. Avenge weak people who got attacked or died or...

*Well that is a kind of like your life wasn't it? You must have wished somebody would have been a savior in your life?*

**Zac** yeah, but I end up feeling myself in the position of Messiah...

*I'm thinking when one's been a kid and exposed to these, horrible things that shouldn't happen to children then I'm thinking sometimes we need somebody who is bigger than just a person*

**Zac** um hm!

*To save us you know*

**Zac** Um! Um! Um! [nodding the whole time]

*Because sometimes a danger*

**Zac** Um! Um! Um!

*Can be so big*

**Zac** Um! Um! Um!

*Can feel so big*

**Zac** Um! Um! Um!

*Yeah? So it kind of makes sense...*

**Zac** yeah, yeah of... in a sense

*It makes me actually think of this other person whom I also interviewed who had also been abused by, by his nanny and, there are some similarities there... and I'd like you to meet him maybe if he comes, he's from England; he's also battled with paranoia and stuff. [...] so, I was just thinking he's um, he's err, he works for the hearing voices. He hears voices, I don't know if you do?*

**Zac** very seldom

Though he appeared to be engaged he told me as I was leaving that he did not want to meet this other man. Reflecting back on this interview, questioning if I lived up to the stipulations set out by Johnsons In-depth Interviewing technique upon which my interview was based upon, I find that on the whole I did. I actively engaged with my lived experience in relation to Zac, sharing my experiences and being honest to myself and thereby him. I consciously made an effort to observe myself and to curb any urge to impose, unfettered, an alternative explanation for mental distress. That I in my mind had been more neutral is a discrepancy, yet listening and transcribing I do not feel that I crossed either his or my own boundary in terms of not being true to him or myself. However I do feel that the dilemma of his medication contra what I perceived as a potentially dangerous remains just that. Should I have said what I felt? Is it ethical not to speak? Would he have listened? What if I had spoken? He has no tools to replace what he perceives as the only thing that keeps madness and suicide at bay. Suffice to say I did not resolve this dilemma<sup>A</sup> during the interview.

Zac viewing himself as a schizophrenic means he has adopted a traditional medical solution for his distress including some common assumptions:

*[...] if you were not to have the drugs, do think that you would be able to work through some of your...*

**Zac** no, no is out of the question! no, no. Without the drugs I would probably be dead by now, or in jail

This belief that Zac has is not unusual indeed the possibility of an early death is well documented, what is debated is why this occurs. Likewise schizophrenia and criminality are regularly placed together. I remember my own fear when I too was using drugs being told and believing that if I was to stop taking them my life would be even worse than it already was and how that trapped me. In fact as a nurse prior to my own experience I too would say the same to the patients in my care because, I realize today, the knowledge I had access to was filtered. This is why I found myself introducing the possibility of Zac meeting Joe as mentioned above. I also noted Zac's many references highlighting the close cooperation he has with his psychiatrist as they combat his schizophrenia together through drug implementation:

**Zac** [...] finally **we** found Abilify so I'm taking 30 mg a day

**Zac** [...] I can only do something when it [anxiety] occurs, taking a benzo or a Rivotril or Oxazepam but I cannot - **we** haven't found anything... a system, or a mechanism, or a drug that stops me having them

**Zac** [...] **We** have tried Seroquel and Solian , they have a... more calming effect

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<sup>A</sup> I have since discussed his medication and description of his anxiety attacks anonymously with a pharmacist I know, who agreed with me. The drug combination and his description of symptoms is worthy of concern so I have since contacted Zac who seemed very happy for my feedback and the offer of discussing his medication with a pharmacist.

**Zac** I know Abilify can cause anxiety, every single medicine can cause anxiety **we** have tried to go down in dosage of Abilify and see if the anxiety attacks change. There is not a pattern there. [...] **We** tried with, as I said Solian and the err... other one what was it...? Seroquel

I cannot help but think of the years that Zac has struggled with mental illness along with the many psychiatrists with whom he has interacted as described here and the overall sense of hopelessness that I felt as interviewed Zac. Not hopelessness for him but his sense of hopelessness. Lack of hope has been a characteristic of severe mental health diagnoses in psychiatry, which is why the recovery movement has highlighted hope as being one of the core concepts promoting potential healing, yet for me disempowerment is a precursor for hopelessness. Having myself spent years trapped in a cycle of hopelessness as a 'chronic schizophrenic' makes me speculate on disempowerment as these comments from my perspective epitomize this. This leads me to speculate further for am I then not being judgmental? Yet having escaped the cycle of hopelessness I know that it is possible and wish it for him which is perhaps why I was not wholly successful in *not* trying to influence him.

Zac has been exposed to a wide range of psychiatric drugs since the time he was first admitted at 18 and describes anxiety as the most debilitating symptom he has. Like his psychiatrist he believes that it is a matter of finding the correct drug, combination of drugs and/or dosage before his symptoms will subside. This places him in the passive role in relation to his illness where his experiences are turned into symptoms robbing them of the potentiality of meaning making and placing them outside of any context, which according to Bracken and Thomas "*can be very dis-empowering*."<sup>75</sup> Yet there are positive aspects to this illness paradigm as well that should not be denied such as being able to surrender one's misery into the hands of an expert who can frame it in an illness context outside of oneself. Zac clearly experiences psychiatry like that, fighting his illness, however; psychiatrists, though aware of social and environmental factors as is Zac, focus predominantly on his biochemistry, yet what happens when it does not help?

In Zac's case he and his psychiatrist have entered into a role of constant drug adjustments and presumably a belief in the potentiality of true relief yet as the years pass this must be difficult to maintain. Perhaps the hopelessness I sensed is in part a consequence of this? Certainly Zac's suicidal thoughts indicate that lack of hope is present:

*So you were still very suicidal then*

**Zac** yeah. I have never gotten rid of the suicidal thoughts and a great deal of my paranoia

*Oh, so how do you cope with your suicidal thoughts because I mean you are still here so you got a handle on it*

**Zac** I have different reasons to stay. The last time I felt myself to be suicidal was... three months ago four and was admitted for three months and I was on the suicide watch for 14 days or something like that and I still managed to make a erm... rope out of the sheets

[...]

*So what er, what keeps you here and what keeps you from the other side?*

**Zac** My erm... my thoughts were, I'm very tired of being ill... I live in sorrow for some losses I have had and... and erm the recollection of many of the experiences that I have had. On the other side I have a daughter so I try to keep myself here for her

This short interview cannot hope to grasp the depth of his reasons for suicidal thoughts nevertheless I speculate that perhaps in another way psychiatry actually feeds into his suicidal thoughts perpetuating them through its illness paradigm?

It is commonly assumed that treatment is based on a scientific objective detachment yet many including Braken & Thomas say psychiatric technologies are laden with assumptions, values and meanings and that: *"current psychiatric interventions are based on the manipulation of meanings, hopes and expectations."*<sup>76</sup> This is dependent on relationships, which have also been reliably identified as being one of the major factors promoting healing in therapeutic relationships and not as previously believed the type of psychotherapy offered<sup>77</sup>. Yet a positive relationship around a disempowering treatment will not lead to empowerment but arguably lead to even greater disempowerment. Indeed Judi Chamberlin has said *"Well, I've been a good patient, and I've been a bad patient, and believe me, being a good patient helps to get you out of the hospital, but being a bad patient helps to get you back to real life."*<sup>78</sup> There is much evidence that accepting a passive role disempowers and places one in a dependent relationship in relation to the one who is active or has more power and in psychiatry this involves the added aspect of surrendering to a stigmatizing internalized abnormality, which only an expert can decipher. However who is to say whether the expert him/herself is not themselves subject to a power greater than themselves? Post and critical psychiatrists would say they were.

However the consequences for Zac identifying with mental illness goes deeper than that:

*[...] do you write as well?*

**Zac** no, no I did when I was younger I wrote things for the newspapers but er... now not anymore and when I came here I really stopped writing and reading

*Oh you stoped reading as well?*

**Zac** Yeah because I lost the ability to read because I can't concentrate on a book any more

*Is that the side effects or because...?*

**Zac** It is my illness. I cannot drive a car anymore, because I get a lot of anxiety and catastrophic thoughts so I'm way too stressed to do it and I'm afraid to drive. I cannot see a movie because I cannot concentrate for more than 1/2 an hour and things like that my life has been...

*You attribute this to your illness or is it...?*

**Zac** It's my illness.

The filtered information available regarding side effects means that what I would perceive as highly likely to be classic side effects richly described when drugs were viewed as alternatives to lobotomy will rarely be

viewed as such today by patients or psychiatry as Zac demonstrates. However, I found it remarkable that Zac does not entertain the possibility of side effects.

I was also surprised at how encompassed by psychiatry Zac is as most of his contact is with community psychiatry. Goffman describes in the institutionalizing process four ways patients can deal with their mortification of self and negotiate the system. These adaptations are "withdrawal", "intransigence", "colonisation" and "conversion"<sup>79</sup>, and help further socialize the person into being a 'mental patient' with subsequent loss of skills. Sue Estroff, inspired by Goffman's ethnographic study of asylum inmates observed psychiatric patients in the community to see, among other things, if was there a difference being in hospital or in the community as community treatment was theoretically supposed to "*dilute those perverse effects of hospitalization*."<sup>80</sup> But she finds that overall, the institutionalizing process carries over into the community for as she says: "*what has society to offer the crazy person?*" This is because people are treated as if they are 'crazy', they live like they are and the burden of proof that they are not 'crazy' rests unfairly with them and she states further that we underestimate the extent of the social reality of a negative identity. Zac would appear to endorse this including having 'converted' his identity as described by Goffman to psychiatry's view of himself and is as similarly described, at psychiatry's disposal:

**Zac** [...] I have a lot of what is in Danish called Sygdomsindsigt

*Illness insight*

**Zac** insight, yeah I've been told, so I participate in a lot of research.

Zac whose beliefs were furthest from my own, presented a challenge for me as I both recognize where he is coming from having been there myself, but now I know alternatives are available that could empower, give back control and choice even without going to the extremes that many might consider the HVN promotes.

The next two interviewees both take medication but are questioning it and thereby questioning psychiatric praxis.

## DOUBT MEDICATION

**Mia** has been in psychiatry for 15 years and has recently moved out of a psychiatric home for the severely mentally ill, to live independently without psychiatry choosing to have her GP support her in withdrawing from the last vestiges of her psychiatric drugs. **Pat** has been on psychiatric drugs for 14 years and both she and Mia have heard voices since they were children.

### MIA

**Mia.** I've never liked taking drugs because I'm also an educated nurse and I know also because I worked in psychiatry and know what medication does to the body and to the system [...] I've seen what it does to people and I feel how it affects me and I've always had great difficulties with it, it's like I had to cross a boundary when I had to take the drugs that was a boundary I had to cross but nobody's ever been able to understand it they just said, "you have to take it, how difficult can it be!" but yes it is difficult!

[...]

*So what happened in relation to medication during the following years, what happened?*

**Mia** I began to be more and more schizophrenic (laughing) and that was why I also got more and more medication...

Mia describes what many others experience; how the effects of the drugs combined with the consequences of being seen through the lens of madness affects one's identity and, if one is also non-compliant as Mia sometimes was, an increasingly aggressive drug treatment, resulting in incapacitation:

**Mia** [...] when you medicate people so strongly they are kept down, it keeps people down, they are not allowed to blossom! they are not allowed to live! they are not allowed to be people!

**Patricia Deegan** a psychologist with lived experience sums up two realities or as Mol would say a vignette from a multiplicity of practices, in her slide<sup>81</sup> illustrating her experience of drug treatment vs. the psychiatrists:

Me	Psychiatrist
<ul style="list-style-type: none"> <li>• I feel sedated</li> <li>• I still hear distressing voices</li> <li>• I can't think clearly</li> <li>• I feel like the meds are controlling me</li> <li>• I'm not myself anymore</li> </ul>	<ul style="list-style-type: none"> <li>• You are not psychotic</li> <li>• You are not shouting at your voices anymore</li> <li>• You are not thought disordered</li> <li>• You are more in control</li> <li>• You have returned to baseline</li> </ul>

Mia also reflects on the time when she was disempowered

**Mia** Because what also happens when you've been in psychiatry for so many years is that your ability to decide is almost non-existent, you get used to just doing what the doctors say, what the staff say and then you just do it so your independence disappears

*So what do you think about that in general if you were to look at it from your perspective the fact that psychiatry decides an awful lot?*

**Mia** That's not in order! [pause] Criminals, [pause] there has to be something that is really important like they've harmed another person or something before you're allowed to take away their ability to decide for themselves but in psychiatry it just happens like the most natural thing in the world. "Now you have to take this and that medication, and now you have to do this and that and the other, and you are not allowed to do this that and the other". It's so few of us that have harmed others but even so...

Though Mia has not committed a crime, she is framing psychiatry's power over her like a punishment and believes if it had not been for a key worker entering her life she would still be in the group home. Mia's turning point was:

**Mia** She was given me to be a contact person for and she could see, because she told me, that when anyone asked me something it took about 5 min before I answered that's how sedated I was by the drugs! But Lene she saw how it was that I was really, really sedated by the medication and she said to me... One of the first things she said to me was "you have to tell me about your life story". "Okaaaay do you really want to hear that so far nobody else has wanted to hear it". Yes she did she really did want to do that. Then she said "you have to, get off these drugs because" she said, "when you are so sedated as you are you cannot work with yourself or your voices" Lene was very involved with the HVN

This was Mia's start to recovery from the effects of psychiatry and a regaining of her identity as something other than a mental patient in her case by being introduced to the HVN:

*What made you change your mind, change your viewpoint?*

**Mia** Partly hearing other people's stories, hearing how so many people saying to me how well they feel now that they've gotten off the drugs. And getting into the voice hearing movement THAT has really given me so much! Not just here in Denmark but also internationally. Hearing people who'd been drugged and then when they are off them how well they're doing

Both postpsychiatry and HVN advocate the importance of meaning and understanding and a significant other, as Alain Topor has shown and illustrated here in Mia's story, as well as for a different understanding to recovery than the classic sense of having recovered from an illness or a state of abnormality to normality. For what if you do not believe you have been mad? Or you have another belief than an illness paradigm to explain your distress? Bracken & Thomas refer to the form of recovery where one recovers something that has been lost or taken away as expressed by psychiatric survivors and actively promoted in the HVN stating, "*In psychiatry, that which has been taken away is the right to talk about one's experiences in one's own way.*"<sup>82</sup> HVN has become a powerful network through having a voice and promoting giving voice to people's stories. This aspect has played a profound role for Mia.

However it is Mia's reflections on the staff reactions to her recovery at the psychiatric home that are particularly interesting as it illustrates the taboo of addressing drugs as being a possible cause of chronicity.

*Okay... So what I'm hearing you say is that there is a lot of joy over the fact that you are blossoming and so on, but that the others should preferably not do the same to put it in a very blunt manner*

**Mia** Well, they are *allowed* to blossom *if* they do it on medication [pause]

*Yes, hmmm. [...] Are you allowed to, allowed! I mean is it okay to say that I'm doing so well because I'm stopping my drugs? Is that okay to tell that to the others or is it preferable that you say that it only works for me and that the drugs are good for others.*

**Mia** No I don't think I should be saying that

*That getting off the drugs is what has helped?*

**Mia** no...

*Is that something you been told or is that something you can feel*

**Mia** it's a feeling I haven't been told it directly. But I won't keep my mouth shut! But it's not only because I'm getting off my drugs that I am doing so well I've also been working a lot with myself but I won't just stand there and say it's because I have worked so much with myself that I am doing so well I want to be allowed to say... so they better... Trying to reign me in, that I won't have! If anyone asks me how I have gotten to where I am then I tell them and that also includes the fact about my medicine and yes that might not be very popular with the staff but they will just have to... I will not restrict myself because they don't think it should be talked about.

Mia highlights the taboo first by answering my direct questions rather hesitantly only to end with a defensive yet fiery statement as if she was breaking rules and I believe she is. Not an official rule but an unsaid one, the one that says medication must remain unquestioned. Psychiatry is used to patients' negative attitudes indeed a whole system is in place to force it upon them should it be deemed necessary, something Mia has been exposed to. Also, the daily revolves around medication as being highly important both on a conscious level; the patients need it and the under acknowledged aspect of caring for people who are profoundly affected by the medicine. Mia causes discomfort for on the one hand the staff rejoice yet attributing it to stopping medication is threatening for what if others should want to do the same and what if it is true that Mia is blossoming because she is stopping the drugs?

It also became apparent during the interview that Lene had had to leave due to her alternative ways of working which included questioning medication:

**Mia** In reality you're not allowed to show very many emotions at all in psychiatry because as soon as you show any, a little anger for example, you get drugs for it. ... that is my personal experience. [...] But one of the things that has happened is that Lene has had to stop working there [pause] They want you have the diagnoses. Paranoid schizophrenic means you belong to that box and that means we have to treat you in such and such a way and that involves medication and it involves..., Lene chose for example to, if I was very, very frustrated or angry she would put me in a car and drive me out to the countryside and then we would walk and if I felt like it I could scream my rage out... instead of saying you know you are a little too emotional right now you are angry you need some sedatives. But that [pause] that wasn't [pause] that wasn't very popular with some of the other staff. [...] Lene was not fired or anything like that she chose to leave because she couldn't work under those [pause] restrictions like the others who wanted to put everything into boxes and so on they

pressurized her and now Pia [active in HVN] has reached the same point... and it's those people who make a difference in psychiatry.

This highlights the real problems professionals face when rejecting the common wisdom and in particular questioning the very cornerstone of psychiatric praxis; medication. This occurs on all levels within mental health not just between psychiatrists but between staff, between patients and the many interactions with the public.

Mia shows us the importance of narrative both her own but also that of others in finding herself and creating meaning and understanding so that she could begin her journey back into the community and begin the process of becoming a full citizen again.

Pat's interview shows us how wrong medical treatment can go when context is ignored in favor of an illness paradigm.

## PAT

Pat chose in her interview to focus on her life story which she prioritized and the consequences that has had in relation to psychiatry and not so much the drugs. Pat was raped and attempted suicide which led to her being sectioned and diagnosed schizophrenic for the first time. Despite staff knowledge of the rape being the reason she tried to commit suicide, it was the focus on Pat's voices that took priority resulting in her diagnosis and force treatment:

*So that was the first time you tried psychiatric drugs.*

**Pat** Yes I was forced to because they sectioned me and I never really had a choice.

Pat was injected with medication and because she was never told why or how they worked she became very paranoid:

**Pat** [...] they put me on 25 mg Risperdal on injection but I got more paranoid, I wouldn't eat, I wouldn't drink, I felt everything was poison; that people were trying to poison me.

*Why do think that was... that happened?*

**Pat** Just because they never told me. I never understood what the drugs do, or did, so I was very sleepy, very sedated and I thought that somebody was trying to drug me to rape me again, so I got really paranoid and I was trying to keep alert. Because I wasn't eating and drinking my lips were all horrible and white and just peeling my stomach acids were coming up so my breath was really bad, I ended up... what's the word? Dehydrated that's the word, so I eventually had to get to the hospital and I was put on a drip because I wouldn't eat.

Because Pat was so afraid of being poisoned she had to find ways of surviving:

**Pat** I knew I had to have some sort of fluid, [...] So I would just go round windows [*and lick condensation off them*] or use puddles in the street and I know that's terrible because that could have caused blooming worse...!

From a psychiatric perspective her symptoms will have reinforced their belief that she had schizophrenia for her actions will have been seen as bizarre and meaningless but will also have been allowed to remain so for the origin of this madness –schizophrenia- is seen as the cause of such irrationality. Thus the staff will have engaged in psychiatric circular reasoning. So, when Bracken & Thomas describe 'psychiatry's role' by stating: "*When we write in your case notes that you have schizophrenia, and we name you a 'schizophrenic', we take away your speech and your ability to name yourself, we obliterate you*"<sup>83</sup> they are referring to this silencing of the patient resulting in a genuine belief that the cause is known. In Pat's case being framed and silenced in this manner resulted in her becoming a revolving door patient spending years going in and out of psychiatry.

On the surface many would think fear of poison, starving one's self and only drinking from puddles or licking windows could be classified as extreme behavior worthy of being called madness. But opening the door to the perspective that human experience is utterly tied to narrative and culture with embodiment and temporality, means that lived experience, with all its complexities, is placed in the center. This creates space for contextual understanding, not just for the individual in distress, but for those trying to help. For Pat did not just carry a story of rape with her, she carried a history of extreme child abuse.

Pat was herself a child born of rape with the result that her mother treated her with great cruelty and violence. So when Pat perceived herself to be in danger in this, from her perspective, institution that called itself a 'hospital' inhabited by people 'attacking her' injecting drugs into her body against her will yet, purporting to 'help' her, she attempted make sense of it. Since psychiatry's discourse silences her, while at the same time not proffering any explanation for their actions towards her, a gulf between realities is created resulting in both parties thinking the others actions are incomprehensible and both create a narrative of understanding to account for the others actions. However it is psychiatry's dominant discourse that becomes the established truth and Pat's truth obliterated as she is forced into the role of a schizophrenic. But because her reality is silenced does not mean that it is gone, indeed she acts in accordance with her reality, clashing and complementing psychiatry at the same time, for if her actions can be deemed meaningless and instead representing an embodied pathology, then psychiatry as a technological enterprise becomes justified.

What if meaning and understanding is introduced and madness can be placed in a context; will that threaten to destabilize orthodox psychiatry as we know it? By opening up a space and giving Pat voice the seemingly bizarre becomes a survival strategy from an embodied history linked to the narrative of her life.

**Pat** I went back to when I was in the bunker, of surviving and water, and what I mean by that was that my mum wouldn't give me anything to drink and what I used to have to do was drink, or put on my mouth the condensation from the window. Because there was a little slit for a window and the only time I could drink was if it had been raining, or it was damp, the condensation off the window was what I was getting. So that was the only thing I trusted. [...] I was locked in the coal bunker [...] and I had to go in there, naked. Sometimes I was allowed my clothes and I could be in there up to 48 hours. The only time I had was the sun as my clock, I had no concept of time. All I knew was it was sunny when I went in or it was night when I went in and I was still there the following night with the following day, so I worked out that obviously, I was there one sun two suns so...

*So that's where you ate, drank, that's where you got water...*

**Pat** She wouldn't always feed me either. I was quite a thin child and I had to hide food... I had to hide it up... - I know it's not nice saying this, my vagina I had to hide it [food] under my arms, between my behind, because if she saw me with food... and I'd even try and hide it under my mouth, anything I could, but that's why she... because she caught me a few times and that's why she would make me go in naked because then I couldn't hide the food, but I hid it up here [points]

*In your vagina*

**Pat** Yeah, my bottom, I know it doesn't seem nice to hide it up my passage, under my arms, and I'd go in and then I had to hide it under the coal, but I couldn't -what's the word? Always find where I hid the food because it was so dark, so I got to use the moonlight you know, the beam and I would try and put it where the light would be so I could find it again

*Oh my God! So what would happen if your mom, if your mom found out you had drunk something or eaten something...?*

**Pat** She would batter me. [...] She would say things like 'you're a bastard, like your dad you look like your dad' just beating me up. I, I, I suppose I became my mom's coping strategy I don't think in those days they had things like rape counseling

When Pat was 7 things changed:

**Pat** So, then we moved house when I was seven, there was no coal bunker there, so she had to find a new form of punishment and that would be bath night, Wednesday and Sunday and when she had me in the bath she tried to drown me and she let me up when I became limp and she'd flush my head down the toilet pan. Sometimes if she was in a bad mood she would wee, or poo in the pan, if she wasn't in the bad mood she was just flush my head and that was a new form of punishment, but... it was scary but it didn't seem as bad as the bunker. That was the new way of punishment.

And Pat's situation changed again at age 13:

**Pat** No my mom died when I was 13 so I ended up in [...] this children's home that I was sent to and who abused us children and who made us do things to children that you don't do to children...

Pat had a childhood filled with abuse yet it was never acknowledged, there was no one to bear witness to the reality that happened behind closed doors. Then Pat is raped and once again her reality is denied and instead she is 'punished' for it, reminding her of her childhood being punished for being a product of rape and trying to survive by any means she can.

In the eyes of psychiatry being force medicated is perceived as helpful treatment for the good of the patient yet for many users/survivors of psychiatry this is experienced as abusive and Bracken & Thomas draw an analogy when they say: "we force into their bodies things and substances they do not wish to be

*inside their bodies in ways that ape the way the rapist breaches the integrity of his victim's body.*"<sup>84</sup> This can make recovery very difficult on many levels yet, being able to give voice, to be heard, to tell one's story are important milestones in this process. So is justice and fighting back which is a central theme of the psychiatric survivor movement throughout the world and something postpsychiatry is committed to supporting as voiced by Bracken & Thomas: *"we must engage with the wider society by standing alongside those who are oppressed or abused. We must bear witness to their suffering and use our position to draw attention to it."*<sup>85</sup> If it was the norm to acknowledge stories like Pat's, then a culture of pathology and the ensuing medicalization would be difficult to maintain, suggesting that yes, the introduction of context and meaning would destabilize orthodox psychiatry. There is much at stake which is perhaps why great effort is made to maintain the status quo of the medical model of psychiatry as described by Mary Boyle and others<sup>86</sup>.

Pat came in contact with the HVN through Max where she now works and has found a new positive role helping others:

**Pat** Today I'm getting there, I'm a lot better now and it's good and Max's helped me tremendously and he's given me confidence. The fact that I am in charge of the office and helpline it's like WOW!

Pat still has contact with psychiatry and takes medication however she is able to oppose their authority having found the power of her voice and support from HVN and others who resist the medicalization of their misery:

**Pat** I'm just on Risperdal now, but they've given me breast milk and the Sulpiride stopped my period and I said to my psychiatrist "can you take me off Sulpiride". Because Max overheard me having a conversation with a friend about my period and he said "Pat I'm not meaning to butt in, but I think your sulpiride it's the same as Risperdal" he said "stop taking them if you can because that's stopping your period." So when I went to the psychiatrist he said to me "well what would you rather be, well in the head or have a period!" I said "well I'd like to be both." And I said "well you being a man I can't really talk about periods to you" so I said "how would you like it if you for example couldn't get it up" and he went "ooo why are you being personal! There's no need to be personal Pat" and I said "I am not being personal, I'm just trying to tell you that, you know if you couldn't perform you wouldn't be happy if, when, you know it's this drug." "Oh we all have to make sacrifices" [he says] and I thought "no".

*Yeah! Well if I was to get back to the drugs does it work or does it do something good for you*

**Pat** No it just makes me sleepy the voices; they [staff] actually want me to go on... oh it's that one it's like the traffic light system, because it can kill your blood cells...

*Oh you mean Clozapine*

**Pat** Clozapine, they want me to go on that. They said that will get rid of my voices and I said no way I can't afford to go on that with a nine-year-old I said no Risperdal doesn't [get rid of the voices], like Max says in his workshop if they give you a wee bit and it doesn't work, a lot

is not going to work. They just want... They're not happy that I've cut down myself because they wouldn't cut me down and I just said to him [*psychiatrist*] I'm cutting down whether you like it or not. Again I got my courage there from Max. The drugs they definitely don't help, they just make me tired the voices are still there and as I say they've given me breast milk and mess up my period.

*So your plan is to try and stop it, or are you fine?*

**Pat** I want to stop it all, I want to be like Max you know, no drugs [...] but I'm doing good because I was on 12 and it's taken me about 3 years to get to 4mg.

Pat's drug reduction tempo indicates she is cautious about reducing them despite her finding them unhelpful and have unacceptable side effects. She is however following the advice from a fellow voice hearer whom she trusts. It is clear she is skeptical of the psychiatrist who from her perspective is unwilling to address her subjective experience and it is interesting that he and staff want her to change to another antipsychotic clozapine which is typically used as a last resort antipsychotic. They continue to focus on her voices and that she is a schizophrenic failing to see that she has found an empowering solution that is allowing her to blossom. This failure to recognize life events be they acts of violence like her rape or helpful solutions like working the helpline which is empowering her, means that this gulf between Pat and psychiatry is set to continue. The question is does Pat need psychiatry and its solutions?

This leads me to the last two interviewees who have chosen to stop psychiatric drugs.

## OFF MEDICATION

**Joe** spent many years in the psychiatric system as a revolving door patient. Prior to that Joe had been the owner of multi-million kr. business but he carried with him a history of undisclosed child sexual abuse from the age of 5 to 13 by his nanny. **Leo** spent many years in psychiatry including time spent in a home for the severely disturbed. Today he works in the mental health system and is in the process of starting his own business and he has been off psychiatric drugs for a couple of years now.

## JOE

*So what do you believe is the reason for you ending up in psychiatry?*

**Joe** I think it was for me when I was abused for eight years; it was the *not* disclosing [...] and it became repressed buried in the voices that were there. The biggest thing that brought me to psychiatry was becoming a father you know I love my kids unconditionally but when my son was born I looked at him and I realised the vulnerability of him and I thought how do I keep this child safe when my parents missed it. The biggest mistake also was I never told my wife about the abuse or the voices. I got three children and I'd be working long hours seven days a week and she would ring me up and criticise me for never seeing the children and I was getting these subliminal messages saying she is trying to tell me that they were being abused because mine was surfacing. You can't go home and say oh by the way I was raped as a kid and I hear voices [*laughs*] I was really, really stuck and that's when the lid really started to

come off. I got all these fears in this box and it started to surface and that was when the voices intensified talking about the abuse

Like many other patients, Joe initially believed that psychiatric services would be able to help him:

**Joe** Well at first I initially I actually believed him [*psychiatrist*] because I think, it being psychiatric services with no understanding of what was happening I knew what the voices were saying but I didn't know what the meaning was and when he said if you take these it will cure you. Now I'd gone from owning my own business within four months to being a psychiatric patient and I wanted my life back so I believed if I took them my life would come back but my life actually started to deteriorate because I couldn't function. [...] It got to the point where I was sexually impotent, I had a lot of akathisia, I was losing weight actually, I was really, really losing weight I wasn't eating, I couldn't be bothered to get out of bed to eat, I was very dark round the eyes. I think the biggest worry that I got [...] I realised I was shuffling I had become a shuffle feet. [...] at that point I started to become really, really frightened. I couldn't shave because of the akathisia I would've just cut my face to ribbons

*Oh wow!*

**Joe** So the more dishevelled I looked the more they put the drugs up because I'd not really responded a real Catch-22 [...] to the point I was taking 25 tablets a day. [...] I was the archetypal schizophrenic my wife couldn't cope with it and her words were, you are not the man I married. I tried to defend that by saying we all change in time but she said you don't do anything, all you do is lie down all day. The most mind numbing thing about it was I wasn't tired but I just needed to lie, because my head was just spinning and screaming. I think the big reality also, apart from the shuffle feet, was my father came to visit me in hospital and he said to the nursing staff I'm really concerned about the amount of drugs you are giving my son. I overheard this conversation and the nurse said your son is taking enough drugs to knock a horse out we can't stop the voices we don't really know what to do and at that point I thought where do I go with this?

Joe, like Zac and Leo, is exposed to psychiatry's apparent helplessness in the face of this perceived illness where psychiatry's only recourse is to increase/adjust the amount of medication. Yet this has far-reaching consequences as the label schizophrenia ceases to be just a diagnostic description but its treatment marks the person physically leading to further loss of citizenship as stigma and discrimination sets in. So rooted are staff and patients in this illness paradigm it becomes impossible to speculate in alternatives, likewise side-effects though discussed are regularly framed as part of the illness rather than being seen for what they are which again feeds into a belief system that an illness exists.

In Joe's case, he lost his family and for a period lived homeless on the streets fully believing he was a schizophrenic and that the mental and physical side effects were a part of this illness:

**Joe.** My life just disintegrated I couldn't function or anything leading to the point when I was on the streets I was so unmotivated to do anything that I would just urinate myself I couldn't even be bothered to stand and pee around the corner! I was really entrenched into this madness role and was fortunate in some respects that I did have children and I didn't want to

lose sight of them. When I did find somewhere to live it was about a 20 min walk to their house and went to see them before they went to school it would take me about two hours

*Wow!*

**Joe.** Because I just couldn't move, my arms were stretched out in front of me and they were locked like a got and indivisible wheelbarrow everywhere I went and I couldn't bend my arms so people were looking at me and mocking me. I realise now that it was the side effects or, is it the *effects* of the drugs really

Moncrieff, part of the CNP who views the medical model and the ensuing psychiatric drug treatment as based on an ideology or false consciousness in the Marxist sense, has in her book<sup>87</sup> studied the effects of the drugs and questions whether antipsychotics are useful for those deemed schizophrenic. Because antipsychotics affect primarily D2 receptors they will all at some point mimic Parkinson's disease however psychiatrists generally try to avoid overt symptoms of parkinsonism referring to a therapeutic level generally thought to occur at 40 to 60% occupancy of D2 receptors. The frontal cortex is one of the major areas impacted by blocking D2 receptors and is the area where the personality is situated, executive functions such as deciding right from wrong, decision-making, morality, emotional memory and rationality are also found there.

Peter Breggin summarises the effects of neuroleptics in what he calls the deactivation syndrome described as emotional blunting, reduced motivation, indifference, apathy, sedation etc., they also affect movement resulting in stiffness, reduced facial expression and physical inertia. Akathisia is a common and extremely painful drug induced mental state of extreme restlessness and anxiety while being subject to a feeling of being disengaged from the surrounding world. Cognitive functions are also dulled, as is memory. Many of these effects mimic the symptoms of schizophrenia as described in the DSM, which is perhaps why staff fail to see that in reality they are dealing with a person profoundly affected by their drugs rather than an embodied illness as Joe so clearly describes:

**Joe** I honestly believe that everyone who prescribes it should take it and it's not just the taking it that's important its the social environment that goes along with it

*Try to describe that a bit*

**Joe** What they should do with it is they should make you take it for a minimum of two months. But put you on a terrible housing estate, where your victimised for how you walk and how you can't; you are using no eye contact, you are shuffling around and then they'll see, actually this isn't schizophrenia this is a consequence of what you put in me body and I think *that's* what they need. Then they would live the experience and get some more understanding on how devastating it is for people

However, this also indicates how successful the pharmaceutical industry continues to be at marketing antipsychotics as beneficial for schizophrenia in alleviating precisely the symptoms that they themselves are causing despite neurological and historical evidence that belies this. This belief may explain why psychiatry is so slow to acknowledge the toll side-effects have on people because they attribute side-effects to symptoms of schizophrenia:

*So one of the things I'm hearing you say is the side-effects of being put on the drugs is actually what people are seeing as schizophrenia...*

**Joe** Yeah they think when you kind of shuffle along and you've got Akathisia, dark around the eyes, you're unkempt, you're unshaved, they think that's schizophrenia and I hear that from so many people in the general public. It's the consequence of the drugs! It's complete apathy you haven't got the drive or the inclination to get up and say I'm going to do something! Because you can't you can't function! you can't be a parent! you can't be a husband or wife or whatever it's... It's just its the most mindnumbing thing you will ever, ever go through.

*Do you believe in the schizophrenia?*

**Joe** No, I don't believe it at all, it's a made up word.

Is there a place for medication? Prof Marius Romme suggests<sup>88</sup> in certain circumstances when emotions are overwhelming medication can be helpful in low dosages to reduce emotions but does not view medicine as a helpful solution for the consequences of trauma. Instead he advocates therapy or self-help groups to find meaning and understanding at what lies at the root of extreme mental distress.

Joe has his own business today teaching and promoting that hearing voices and other extreme states are meaningful, and that there are other ways of understanding human distress. Yet, I am struck by the similarities of his story and that of Zac's in that they both experienced sexual abuse by their nanny, both experience similar kinds of paranoia yet while Zac has chosen to accept the role of mental patient Joe has chosen in emancipatory trajectory. Joe uses similar tools to Zac however by not framing them in an illness paradigm Joe has regained agency. E.g., both Zac and Joe have had olfactory hallucinations and while Zac sees that as a symptom of schizophrenia, Joe has attempted to find meaning setting himself free:

**Joe** I think the biggest thing for me [...] as I was coming off my drugs my experiences did get worse and I was trying to get an angle on them. My abuser used to make me eat my own faeces and I sat in a cafe one day, I'd gone in there to have something to eat and as I bit into this food it tasted like human faeces and I spat it out and I said you're making me eat shit and I stormed out. It took me a long time to reflect on it why would they have done this to me? But what it was -it wasn't that obviously she hadn't served me anything like that; but what had happened was the lady who served me was wearing the same perfume as the woman who raped me so I'd made that association *she* could have been serving me this like when I was a child. But once I could make sense of that I thought actually no...

Joe has learned to understand his early warning signs and act upon them taking control and ensuring that he does not succumb to paranoia:

**Joe** Recently when I went to Australia I went very paranoid the voices were very loud I was getting really suspicious ideas about my wife. I wanted to go off on my own she wanted to come with me and when I kind of sat down rationalised on it, reflected on it, I realised I had booked in too much work! And I could make sense of it then. So it wasn't that I wanted her

to go, it was I didn't want all that pressure! So the voices were saying don't be stupid calm down on what you're doing!

*They are actually a tool, something helpful as opposed to a symptom of some...*

**Joe** To me they're my early warning signs. When things get bad voices increase and basically saying "we can tell you off because what you're doing is you're creating a vulnerability in yourself. Don't be the child that was vulnerable you had no control then, you've got a choice now." So they are actually serving; very metaphorically at times, but they do serve a protective purpose really.

Zac like Joe attempts to use his rational self to check the reality of his experiences but contrary to Joe, Zac frames any deviance from the norm as a sign of his illness and helpless in the face of it, succumbs to madness:

*So how, when you've had your paranoia [...] How have you erm... managed to rationalize yourself out of it?*

**Zac** I cannot

*You can't?*

**Zac** no, no, I at some point look back and think whoa, this is, this is getting out of hand. One of the times for example when I had an episode like that I ended up calling the police and telling them that I surrender and they can come and get me and stuff like that they knew, that I was psychologically... [*Symbolizing with hand movement madness*] So they said I should call the doctor and from there...

Two interpretations of what could arguably be described as similar symptomology's yet the one disempowers, and the other empowers. The one supports an illness paradigm and the other opposes it and yet psychiatry in trying to both justify its illness paradigm and promote hope can result in contradicting itself:

**Joe** when I received a diagnosis of schizophrenia the psychiatrist said you were a chronic schizophrenic and you will never ever work again go away and enjoy your life. I was thinking well how the hell do I do this. But it became a little bit of a contradiction because he would say if you take these drugs they will cure you. Well if they're going to cure you why can't I work again so you are getting all these kind of mixed messages.

This leads into the final interviewee Leo who as a pharmacist was particularly challenged having to face the paradox of drugs as not just a chemical entity but also of a social and political nature.

## LEO

Leo initiates stating his loss of faith in a psychiatric illness paradigm but also why he initially believed it to be true:

**Leo** I am an educated pharmacist and my mother is a neurologist so quite similar to psychiatry even though there is quite a big difference between these two specialities

because with neurology you know that the person is ill with something real you don't know that in psychiatry. I grew up knowing that the way one cures an illness is through the use of medication and this also included psychiatric problems [...] So if one is psychotic then of course you take something for the psychosis! [...] So I actually experienced being admitted as a positive thing.

Leo is referring here to the contentious crux of the matter, the lack of evidence of a tangible illness which psychiatry insists exists. However Leo because of his background assumed that the scientific foundation behind psychiatric treatment was sound as he explained when I asked him

*What was it that kept you taking them despite the side effects?*

**Leo** I looked specifically at the science behind psychiatric drugs [*as a student*] however because it wasn't something that has interested me I hadn't looked deeper to see how bad, how non-existent the scientific *basis* is! It is floating on hot air like a hovercraft keeping itself afloat on an air cushion. There is no foundation, it's just something that is stated but because I was so used to other medicines being well-documented I assumed it was also well-documented within psychiatry including weighing for and against side-effects [...] I belong to the small percentage who continued to take them after two years because I was so trained in thinking that was the solution

Leo is describing something I recognize; the belief in one's own profession and the time it takes to accept that it is not as it seems. In Leo's case, he is trained to look at standards and norms and viewed psychiatry initially as a technological enterprise subject to the same scientific rules as other medical specialties based on the assumption of a tangible brain disease. However today he, like Bracken & Thomas, is critical of standards in psychiatry viewing them as subject to corruption:

**Leo** as a pharmacist you spend 5-6-7 years studying medicine learning all their aspects so of course we know what qualifications are needed for a drug to be accepted and naturally one assumes the same standards are used in psychiatry. However when you look closer you find out that the standards, i.e. clinical testing is different, poorer, that they are tampered with

Naturally this 'tampering' is not just a preserve of psychiatry but record fines indicate that it is a problem. Likewise Leo is critical of the diagnostic standards viewing them as haphazard:

**Leo** I don't necessarily agree with how a psychiatrist describes me, but then they have not been in agreement with each other because I have cycled through 8 different diagnoses. A little like today's special. What medicine do we feel like giving Leo today? Then I have such and such a diagnosis. Is there something we haven't tried before? Then we will try that

*So how do you experience the diagnostic system?*

**Leo** completely chaotic

Psychiatry like other scientific endeavors emphasizes evidence-based medicine (EBM) and gold standards through using objective research protocols where the ideal is a "meta-analysis of randomized clinical trials offering probability estimates of each outcome"<sup>89</sup> resulting in guidelines relating to clinical praxis. Though

detached objectivity is the ideal, this is rarely possible when producing guidelines and the preferred method is consensus meetings where experts gather to discuss conflicting issues. Lack of transparency has been a common critique and this has been particularly evident in psychiatry when creating guidelines for the DSM. For example Herb Kutchins and Stuart Kirk in their book, **Making Us Crazy** state: "The developers of DSM assume that if a group of psychiatrists agree on a list of atypical [new] behaviors, the behaviors constitute a valid mental disorder. Using this approach, creating mental disorders can become a parlor game in which clusters of all kinds of behaviors (i.e. syndromes) can be added to the manual."<sup>90</sup> Lynne Rosewater a forensic psychologist sitting in on the DSM consensus meeting recalls how at one point one of the criteria for Masochistic Personality Disorder tabled by Robert Spitzer was being discussed: "Spitzer's wife, said, 'I do that sometimes' and he says, 'Okay, take it out.' You watch this and you say, 'Wait a second, we don't have a right to criticize them because this is a 'science'?"<sup>91</sup>

Never the less standards create subjects and standards are what defines one as ill, something the person must be suffering from to justify being given a pill and in that light it becomes irrelevant whether the illness is socially constructed or bacterial. In fact the labor market too demands to play a role in the standards of what constitutes illness involving itself in when a person is ill enough to warrant treatment and as the psychiatric diagnostic standards expand spreading into what used to be deemed the normal population, the experience of *feeling* ill begins to play a significant role. However, though someone can feel or become physically ill, psychiatry is unique in that they can say a person is ill and initiate/force treatment.

**In Standards Recipes for Reality** Lawrence Busch argues that "*if standards are all about power in a society, then they must also be about ethics and justice.*"<sup>92</sup> He argues that separating these issues is not possible despite a proliferation of standardizations and organizations believing that their standards are not value driven. Indeed he argues that we have become 'serfs' to consumerism and that it is our neoliberal driven market economies that are creating an explosion of standardizations. Neoliberalism requires that to succeed, the laws and standards that protect a model, for example the medical model of madness, and ensure that its reality mirrors its functioning they must "remain largely *invisible* to actors in the market society."<sup>93</sup> This is interesting as Busch further states that the Achille's heel of neoliberalism is to bring in debates and dialogues and thereby bringing into consciousness the implications of standards and laws. The medical model of psychiatry has gone largely unchallenged very much driven by market forces primarily controlled by the pharmaceutical industry which have successfully created an appearance that purports care yet are in reality scrupulously<sup>94</sup> profit orientated.

**Leo [...]** One forgets that the pharmaceutical industry is the world's second-largest industry in terms of production, but is the most profitable business of all. So if you as a business have a drug then you find some extra symptoms that it can be used for, you find some extra indications.

A neoliberal society will because of its very nature allow for opposing standards such as is seen by NGO's or here critical and post psychiatrists, HVN and other user/survivor organizations to develop and they are now bringing in these debates.

Busch concludes by asking an important question, "are standards the most appropriate form of governance?"<sup>95</sup> Postpsychiatry would posit no, in that their primary focus is the uniqueness of the

individual in a contextual meaningful manner bound up in relationships. Trying to standardize human misery through psychiatric technologies which are themselves laden with meanings and priorities involving EBM is inseparable from ethics and values. Therefore Bracken & Thomas argue that instead of trying to make disagreements disappear when e.g. creating diagnostic standards through consensual meetings, those discussing should acknowledge that the disagreements are reflections of different perspectives and like their patients represent subjectivity. This they state highlights that it is a problem of interpretation rather than an attempt at standardization which is why they suggest that perhaps we should be looking at narrative-based medicine which focuses on the uniqueness of each human being rather than a standard to be imposed on all.

Leo as an expert in the field of medication becomes subject to a system with which he gradually becomes disillusioned as he gains knowledge of the lack of EBM and standards that are not founded in the standards set out for good drug based praxis. This results in him stopping the drugs and leaving psychiatry. In the process of stopping the drugs he discovered:

**Leo** when I looked at the scientific literature I saw there was nothing there on how to taper off antipsychotics

Leo describes how he stopped the drugs and what inspired him to do so:

**Leo** I knew that the way I experienced the world while I was on drugs was not right. It wasn't so flat where nothing mattered. But there was something secure about it, easy, I never got angry, I was never sad but I was never really happy either. [...] but then I got a job where I got to see there was another alternative that one can actually manage without medication! [...] I had read Arnhold Lauveng which was super interesting hearing how she could manage without medicine. [...] so suddenly I saw that there was this other way.

*What was your biggest sacrifice?*

**Leo** That I couldn't read. This is in relation to reduced sexuality, shorter life etc, it's a long list that one can choose from but for me the worst was suddenly not being able to read, not being able to think and remember. I remember being tested by some psychologist and I couldn't remember even the short sequence of numbers [...] that was frightening. That was not normal for me.

*Did you experience yourself as doped?*

**Leo** yes absolutely [...] when you talk with people and 15 seconds pass before that person answers then you are already put in the category of being dumber. My uncle said it very clearly, that he was happy to get me back after a long period of me being dumb, sweaty and dribbling, and now I was myself again and that was nice to see.

*Did he say that!?*

**Leo** yes, yes and it was really sad and upsetting to hear at the same time, but it was nice the fact that I was myself again.

*When you chose to stop what did you notice?*

**Leo** many different things [...] colors suddenly became colors again, not black and white. Color intensity is removed [by the drugs] but suddenly there were colors again and smells and sounds. And I could fall in love, I could also be really sad, I could, tons of things, my desire for sex returned, the belief that it would be nice to be touched by other people. But it was also very confusing

Leo is nuanced in relation to drugs in that he sees them as being potentially helpful if he was emotionally overwhelmed:

**Leo** I would not be afraid to take them for a short period of time [...] but I am talking about a completely different type of treatment management [...] I swear I will never ever let a psychiatrist come and control my medicine again

Leo also describes his typical day as a patient contra today:

**Leo** when I was on leponex<sup>A</sup> I had two alarm clocks to ring at 4 in the morning to ensure I went to the bathroom so I didn't pee in my bed, one of the side effects of leponex as well as change my pillow case because I dribbled, another side effect. Then I would get up -I lived in a psychiatric home then- at 7.50 and went down and ate breakfast at 8 and then a bath. Some days I would go out and shop for food and make it. We saw the news at noon and I drank coffee. At 2pm I had a 3 hour nap then I saw tv till 9 and then I went to bed and slept until 8 the next day

Today:

**Leo** now I sleep about 6 hours, so I have so much more time available especially as I now work between 8 and 10 hours a day. I come home see friends, make some food, wash some clothes see a bit of TV, talk, read and then I go to bed. So it is a completely different day! And all those things like washing clothes was a big project before. But today its nothing more than throw it in the washing machine, it's not a project its nothing in it goes and then I hang it up

Leo describes very clearly his life as a recipient of psychiatric drug treatment and a life when he no longer receives treatment and it is hard not to be struck by the astonishing difference in the two worlds in more ways than one. From Leo's perspective the drug treatment handicaps so much so that he ceases to be able to function and must have 24 hour support in a psychiatric home. From psychiatry's perspective they are dealing with a severely disturbed schizophrenic who requires their 24 hour help. It also becomes clear that psychiatric homes are a necessity when people have become so handicapped thus creating jobs based on helping these individuals and serving society by taking responsibility for them. It makes me think if we are

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<sup>A</sup> Leponex is commonly viewed in psychiatry as the last resort treatment when all other forms of drug treatment have been tried

to take Leo's perspective seriously then we must acknowledge postpsychiatry's insistence in questioning the medical technologies of psychiatric praxis. The question is are we ready to do so?

## CONTEXT OF TRAUMA

Identity exists in relation to contextual life and if a meaningful interpretation of one's life is denied and replaced by an authority's ability to define the other, then the person becomes both a subject and subjugated, for as Foucault says:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word "subject": subject to someone else by control and dependence; and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to.<sup>96</sup>

Between 70 to 90 % of people who hear voices do so following traumatic events<sup>97</sup>, yet hearing voices and other unusual experiences continue to be seen as symptoms of an illness which subjugates through ignoring the significance, meaning and context surrounding such experiences. Why is it so hard for psychiatry to acknowledge trauma? I believe my 7 interviewees represents some of the different ways psychiatry attempts to address trauma or not.

For example, Pat's experience of being labeled and her rape downplayed the first time she is sectioned because she tried to commit suicide after the event, is one way psychiatry approaches trauma.

*So just to get there, did you tell them that you'd been raped?*

**Pat** Yes they knew that I was raped because it all was to go to trial as well, but I didn't go to trial but...[...]

*So, so what was it like to be diagnosed as schizophrenic when you come with such an awful experience as being raped?"*

**Pat** It's like what! I didn't even know what that [*schizophrenia*] meant, nobody told me, nobody told me what it meant, or what it was, and they just said that I had this mental illness..."

Not only is the significance of her reality denied, but the event within psychiatry is recast to suit an illness paradigm rendering the crime perpetrated against her body as secondary and, by force medicating her on the grounds of alleviating the symptoms of schizophrenia, re-abusing her body. This had tremendous consequences for Pat.

Lou experienced a similar situation though in his case his rape occurred in childhood at age 7:

**Lou** I, I, all I, I remember was feeling happy that it;... and then blacking out and then waking up and I, I had, I had I, I used to play Egyptians ancient Egyptians

*Oh yes yeah*

**Lou** and I had this ancient Egyptian tunic I had made out of an old dress of my moms and used to go around playing in it, ancient Egyptians and I used to go down by the river in it and stuff, playing all these games and then all I, all that happened was I felt someone behind me. I got pushed to the ground and when I finally came round my battledress was covered in semen and I went upstairs to hide it. I mean it, it made me feel VERY confused yes. And then up came the Ritalin and I was sort of super speeding maniac you know

Lou's behavior presumably changed becoming more problematic and the Ritalin indicates he was viewed as suffering from a childhood mental illness, probably ADHD. He did not receive help for the rape he was subjected to:

*So, were you alone with that experience?*

**Lou** Yeah, I couldn't tell my mum. I don't talk about it that often at all but I want people to know that many schizophrenic people have been sexually abused

This denial of the significance of embodied trauma is not a contemporary phenomenon stretching back to Freud and his theory of seduction. The general consensus in the psychoanalytic community is that Freud retracted his seduction theory due to a failure of moral courage, substituting it for a theory that the clients, often women, coming to him with stories of sexual abuse, were based on fantasy. David Smail in analyzing Freud's correspondence with Fliess<sup>98</sup> draws an interesting conclusion based on the most mundane of things, money. Freud referred often to his economic situation, a source of great worry and when he began to earn money from his clients of whom many were women dependent on men to support them, it would have required great courage to continue to pursue a theory which would likely have cut off his source of income. Certainly by redefining sexual abuse as fantasy the burden of blame is moved from within the community to the individual and Freud could secure a source of income while not provoking the hand that feeds so to speak. Smail therefore makes the pertinent point that "power and interest as *inescapable material factors* [...] have just not figured in psychological thinking..." and he argues "reflect the operation of repression on a massive scale"<sup>99</sup>. I would contend that Smail's interpretation for why Freud chose to negate the stories of abuse is similarly prevalent in today's commercialized business of helping those who come with similar stories of distress based on abuse. By placing the burden of responsibility inside the person allows psychiatry to objectify and act upon the individual, something not possible if responsibility was to be found in the external environment. However, just as Smail posits with Freud, so there are tremendous mutual economic benefits for psychiatry and the pharmaceutical industry and it becomes both their interests to focus on the brain defects. Never the less, being an industry with many actors, it is multifaceted and many stand to benefit, not just psychiatry but also the patient. For example, Leo expresses in his interview that medication saved his life despite his disbelief in psychiatry:

**Leo** The very efficient medicines, those said to be very effective, give about a 10% reduction in symptoms, which is not actually that much measured by psychiatry's own scales. [...] I can say

though, that I have had periods, where I have been happy to have had that 10% reduction because I felt so bad that if I had been 10% worse then I would be dead."

Sometimes trauma is not acknowledged by the person themselves because psychiatry is unable to offer tools to help decipher the symptoms as described here by Mia when she was admitted into psychiatry under duress.

**Mia** One day when I had a day off they turned up at my house with the Dr from my workplace and then they said that "we have arranged that you are to be admitted"; [...] "and we've noticed that you are doing really badly and we've noticed such and such and such". For a long time I knew that there was something that was wrong but I knew..., I just had to fight the voices, I mean I had been doing that for years anyway so, so... I wouldn't admit to myself that I was probably psychotic [...] So I said oh all right I accept so as to avoid forced admission and that's when it all started really, my proper 'psychiatric career' from then onwards where I just... [Pause] And so, I was asked if I heard voices and I told about them for the first time in my life to someone that, 'yes I did' and it was written down in the journal and then it was never talked about again! I don't know how many times I've been asked do you hear voices and I say yes I do and then it is noted in the journal and that's it.

The traumas [including rape] were not seen by Mia or psychiatry, nevertheless they are embodied as expressed through the voices of the different selves yet because these selves are met by a paradigm of care that sees voices as symptoms of schizophrenia they remain meaningless and out of the grasp of the potentiality of sense making. It was only when Mia got access to HVN that she began to decipher her voices.

The psychiatric belief system which sees trauma as events that have occurred but playing little relevance to the mental illness leads many patients to adopt that paradigm themselves, so trauma, though acknowledged, appears disconnected to the symptoms of distress such as when Zac describes he is suicidal as an 8 year old:

*But how come you were at eight suicidal? You thinking as an eight-year-old...?*

**Zac** Yeah!

*Wow! Can I ask what was happening in your life?*

**Zac** I was abused

[...]

*So do you see yourself as being ill because you have an illness as in you know..., or do you see it more related to your life story?*

**Zac** no I think I am [pause] I am completely convinced that I am ill, that I was born ill, and that my life story made it more severe and also it was a very bad combo but I don't think I'm ill because of what I experienced, I think I was ill before

For others, the trauma is so overwhelming that dissociation occurs, like a splintering of selves, yet in Ben's case his trauma is acknowledged as he receives help to piece together his life:

**Ben** I didn't recognize it as dissociation until I met Kat [*his key worker*] actually, and we spoke about it

**Kat.** Kat told you [*Kat laughs*]

**Ben.** [...] But coz before..., before we [*his different selves*] had psychological therapy and before we taught us how we began to talk about my problems and stuff, become more aware of what some of the experiences I had had were associated with dissociation and kind of..., you know [*pause*] dissociation from severe trauma and severe emotion and very... powerful emotions

*So did you, do you experience yourself becoming your voices? Or are you aware of yourself, is it a complete dissociation so are you blanking out?*

**Ben.** Do you mean now?

*Oh no not now, but when you've experienced dissociation?*

**Ben.** I can't really explain it really, it's a bit strange because what happens - because basically [*pause*] the big thing that kind of sticks out in my mind is when I was 16, when I was 16 which is when the voices first began, around the age when the voices began was when I dissociated from, well [*pause*] which something that basically was the last day I spent -last evening I spent at home, which was very difficult for me, very traumatic and basically erm... I erm... I was...I was... sat erm...

In Ben's case, entering into the arena of trauma by deliberating his own dissociative behavior resulted in him losing his previous clear grip on speaking coherently as he entered into the pain of his memories. Kat who supports him in the daily, took over the interview to help him:

**Kat.** Do you want me to help you?

**Ben.** Yeah

**Kat.** You found yourself outside didn't you?

**Ben.** Yes

**Kat.** Without your clothes on

**Ben.** Yes

**Kat.** And you weren't quite sure how you got there

**Ben.** No...

**Kat.** (*To me*) He wasn't quite sure what had happened

**Ben.** No...

**Kat.** (*To me*) all he remembers was being outside and being naked

**Ben.** Now that's one extreme form, another what I have also discovered as well is..., what I think maybe what dissociation, if that is possible is me being when I was [*pause*] basically when I was, basically with the mirror thing kind of... when I was kind of having difficulties looking in the mirrors coz that started when I was about eight or nine around the age of eight stroke nine years of age. Basically I found it hard, coz when I was looking into the mirror I didn't recognize who it was at the time and soon that after for a period of time, for quite a long period of time was kind of not being able to... not being able to... you know like...

**Kat.** Marry the two things up, who am I and who is this

**Ben.** And recognize who it was, yeah

*Oh right umm...*

**Kat.** Do you want to talk about your latest experience that you had when you when you are standing up and down you do you remember when you are telling the group the other week...? When you were laughing and then crying?

**Ben.** Yes the latest experience of dissociation happened about, about a month ago

*Yeah*

**Ben.** When sorry Kat

**Kat** that's alright

**Ben.** (*Tone of voice high pitched talking fast he appears distressed*) ...Was when I was basically laughing and then I was crying, and then I was laughing, crying, laughing, crying and I couldn't, and I couldn't, and I couldn't, like switching between the two very, very quick and I couldn't, and I couldn't stop, and I didn't know why I was laughing and the next second I was crying, and I didn't know why I was crying, do you know what I mean? It was very, very strange, very sad, the cycle was laughing at something and then I was crying at something, and I don't know what it was, and I can't remember what it was, and I didn't know, don't think I knew at the time what, what was going on I was..., is kind of, I didn't really understand it really.

**Kat.** (*To me*) he was standing up and sitting down

**Ben** ...standing up and sitting down, I was standing up and sitting down and kind of all over the place in my mind kind of, my mind...

A few minutes later Ben terminated the interview<sup>A</sup> and left with Kat. My assumption (as I have not been able to follow up on the interview) is that this exchange regarding his dissociative experiences linked to his

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<sup>A</sup> I have been in contact with him, both that day and twice by email (with Kat) to check if Ben still feels OK about being a part of my thesis and he is.

trauma(s), was too anxiety provoking. As an exchange this dialogue is interesting. On the surface the dialogue is about dissociation linked to undisclosed trauma, yet entwined within the dialogue is another discourse, that of power. Kat has been able to take a patient from a closed forensic ward to a radical conference openly critical of traditional psychiatry and this is unusual. Ben is dependent on her and Kat is clearly protective of him, at the same time it is clear she wishes him to do well in the interview, which is why she steps in to help him when he shows signs of difficulties. Though Ben initiated the dissociation discussion had we been alone and because I did not know him, I would have changed the conversation to a neutral subject as soon as I was aware of his distress. However, I was not aware at that point of Kat's wish for him to do well at the interview. She placed me in a position of power; while I placed her in different position of power based on her relational role towards Ben, thereby allowing her to, briefly, take over the interview. Power here is a fine play of events, occurring on many levels all interrelating to the background discourse of psychiatry:

"The exercise of power is not simply a relationship between partners, individual or collective; it is a way in which certain actions modify others. [...] In effect, what defines a relationship of power is that it is a mode of action which does not act directly and immediately on others. Instead it acts upon their actions: an action upon an action."<sup>100</sup>

Together we, in deferring to each other's roles, subjugated Ben, forcing him into a confessional position, something Foucault describes when he looked at the history of religious confession, which then moved into the medical domain and later the therapeutic domain. Nikolas Rose<sup>101</sup> further describes that the confession form found in therapeutic settings including psychiatry is not so much about approaching the whole person but more an extension of professional control and discipline. By compelling the person to disclose themselves, by confessing 'the truth' a more profound subjectification can occur in that the person is opened up to surveillance, judgement and normative evaluations. Goffman too, describes confessions but as being a part of the mortification of self:

"On these occasions the inmate has to expose facts and feelings about self to new kinds of audiences. [...] New audiences not only learn about discreditable facts about oneself that are ordinarily concealed but are also in a position to perceive some of these facts directly."<sup>102</sup>

Certainly, it is clear by Ben's reaction that he was exposing himself and the change in his presentation of self was directly visible to me, his new audience. So though Ben's trauma, contrary to many others within psychiatry, is acknowledged, and he receives therapy, it is counteracted by the subjugation of self. What this also shows me is that though I may wish to remain outside of the disempowering aspects of the discourse of psychiatry I too can quickly become enmeshed within it.

On other occasions, staff can play an important role even though traditional psychiatry attempts to explain the effects and consequences of life events and the multiplicity of realities that this engenders by reducing this to one type of knowledge, a modernist enterprise. This is done by asserting that meaningful human behaviour can be explained by non-meaningful entities such as genetics and neurotransmitters, which allows for a technological framing of problems described in terms of decontextualized symptoms requiring experts with access to privileged knowledge. However, it is important to note that some patients, are fond of the disease concept because it reinserts meaningless experience into a meaningful

narrative of cure. Distributions of meaning and meaninglessness are multiple. Postpsychiatry viewing mental distress as meaningful; where the importance of bodily, cultural and temporal context is indisputable, as is the validity of different perspectives, or as Mol would say multiple practices and realities, means it departs radically from traditional psychiatry. It is however, within this context-centred approach that meaningful help can often be found as described by Joe who was sexually abused from an early age:

**Joe** [...] the great thing about Mary, who was an occupational therapist, was she normalised my experience, she wouldn't talk about schizophrenia, she talked about Joe. What she did was absolutely amazing! She told me about her, she told me about her stresses and the trauma she'd had in her life and I suddenly thought this woman does understand, because I'd always seen workers as not having feelings and emotions [...]

Mary normalizes through 'becoming human' and she does that by entering into a relationship of sharing which helps normalize Joe's experience by opening up for meaning and context. Joe is allowed an inside view that what he experiences is understandable and that workers as the purveyors of normality exemplified by Mary also have problems and distressing events affecting their daily lives. In other words, the illusion created by a culture of help based on professional expertise exerting ministrations on the patient whose problems are reduced to and embodied in an illness paradigm, automatically exonerates the expert, otherwise they by definition would have to be ill too. She, by breaking the rules of professionalism, by moving away from a technological modernist interpretation of Joe's situation and embracing aspects not valued by orthodox psychiatry, gives Joe access to other perspectives, other realities, expanding Joe's patient world and ultimately playing a profound role in Joe leaving psychiatry behind. Her actions are intuitively 'normal' and represent, what is occurring in the everyday interaction between people also when they are distressed and context is known. To introduce this form of normality is viewed as abnormal in orthodox psychiatry and yet that is what many different actors want, from patients, families, staff, to groups and organizations such as HVN and CPN, yet a technological modernist interpretation of mental distress and trauma prevails, why?

## REFLECTIONS ON TRAUMA

Clearly, trauma so prevalent amongst those diagnosed as schizophrenic, challenges the assumption of meaningless symptoms caused by an, as yet, undiscovered illness nevertheless, the insistence of a medical explanation continues to be upheld and is worthy of further exploration.

Could it be that one of the overriding problems of addressing trauma on the wards is staff fear? The psychiatric work place is a modernist enterprise where the overriding focus is a technological paradigm of care based on a biomedical interpretation of mental distress placing staff in the role of the experts in relation to the pathologized individuals. This means staff are ill equipped to address the oft times horrific life stories that these pathologized individuals carry with them. Being placed in the role of the expert has meant that if a patient should begin to disclose trauma, staff often feel that they should somehow fulfil this perceived but unknown expert role before allowing the person to disclose these events. Because this role is unknown more often than not, staff avoid entering into the arena of trauma by either not allowing room for trauma disclosure or suggesting that the person should speak to someone with more experience such as a psychologist. Thus one could say that the arena of trauma becomes a no-man's land.

The fear of opening up this 'no-man's land' is perhaps one of the most reported fears discussed by staff at conferences and in teaching situations, where the perceived consequences of so doing will make the patient's situation worse due to staff fear of not handling the disclosure professionally. The limbo that trauma finds itself in exists within what Foucault describes as a heterotopia of deviance, a place where people whose behaviour does not adhere to the norm. Yet, it can arguably be said it is precisely because of this no-man's land of trauma that results in patients finding themselves in the heterotopias of deviance. Two elements, among others, play a role in avoiding addressing trauma apart from the very real problem of a modernist workplace. The one is the fear of going mad oneself, understood from the perspective that if context and meaning can be removed then meaningless madness lends itself very well to an illness paradigm and madness as a personal risk is removed. This can in part help explain the persistence of an us/them culture and also why dehumanizing treatments continue to prevail despite staff often being keenly aware that life stories are a big element in their patients' lives. This leads to the second element that of addressing trauma. If staff were to address trauma as meaningful and understandable and place the person's words and actions into a meaningful context, they risk having to question the paradigm of care that they work under and if they were to do that they come into conflict with the same authority that their patients often dispute.

On a similar theme, historian Kathleen Jones, elaborated upon by Bracken and Thomas<sup>103</sup> suggests that the reason why psychiatrists might distance themselves is that the medical model protects psychiatrists from having to engage with extremes of human pain by allowing them to separate themselves from the overwhelming social contexts for which they can do little. Thus, they are protecting themselves by using the medical model as a coping strategy by pathologizing human distress, while at the same time placing themselves in the role of the expert. From that perspective, it gives psychiatry tools to control illnesses where behaviour pertaining to the human distress is reinterpreted becoming symptoms to be treated.

From an academic perspective Mary Boyle<sup>A</sup> Emeritus Professor of psychology, part of the critical psychological network, has an interesting perspective, proposing that it is naïve to suggest that psychiatry's neglect of social context and life experiences is a mere oversight and that all that is needed is that they be informed. She posits that it is necessary to see psychiatry's blind spot to social context as a highly developed defence mechanism for their own survival. What is it about acknowledging social context, life experiences and people's environments that is so threatening to psychiatry? There is of course no one answer but Boyle believes one of the major reasons it is so threatening to psychiatry is that the justification for the medical model's existence is based on the importance of social context and life experiences as **not being** meaningful and intelligible. Like postpsychiatry, Boyle refers to form and content of emotional distress as being inseparably connected to life events yet, psychiatry, by seeing these behaviours in a pathological light, can justifiably say that these behaviours are not subject to the same rules as "normal" behaviour and thereby use the medical model to explain them by. However, psychiatry must continually defend itself from the equally valid explanation for "normal" and "abnormal" behaviour, namely that of social context, life experiences meaning and understanding.

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<sup>A</sup> Mary Boyle is part of critical psychology which in the UK has close links to critical psychiatry through the Asylum Collective. Critical psychology is a subject taught at a number of universities in the UK.

Boyle outlines the methods she sees employed to maintain this status quo. She has divided the avoidance strategies into what she calls 'pure avoidance' and 'safety behaviours' where the most obvious avoidance strategy is converting distress into symptoms and disorders and focus exclusively on these, removing any reference to context, meaning and understanding in the process. This can be seen in the vast quantity of research that is available and continually being produced where people are discussed, often in detail, but without mentioning their lives at all. The methods used are<sup>104</sup>:

1. Creating vast amounts of data using scales to measure and compare people's deficits and see if there exists correlations.
2. To focus on people's brains and not on their lives in other words perceived brain abnormalities, chemical imbalances of the brain, brain scanning etc.
3. Study symptoms, symptom clusters, relationship between symptoms and diagnosis, symptom outcomes and so on, again all without mentioning people's lives.

These methods have been successfully implemented having the right aura of being scientifically sound being based on the same methods employed to study physical illnesses. Also, the allure this comparison has to align mental distress with actual physical ailments should not be underestimated either on the individual level with the appeal of the quick fix in terms of a pill or, on a societal level where the outward signs of distress are interpreted as internal pathological events releasing society from responsibility and guilt.

Certainly Read and Geekie's<sup>105</sup> literature search on the subjective experience of schizophrenia and my literature search on the subjectivity of medication would appear to support Boyle in that context, subjectivity and life experience is very underrepresented in the research literature.

What happens in situations when context cannot be entirely removed Boyle asks? This is where what she calls 'safety strategies' are employed. Context is an ever-present threat and so situations arise where it cannot be ignored simply because there is so much powerful evidence, linking mental distress and suffering to social context. It becomes suspect if complete avoidance of social context and life experiences occurs so, the next key strategy is how to mention social context without it ever being linked to being the major cause of the distress. A very successful strategy to incorporate and neutralize social context, which has come about in recent years, is the *Vulnerability-Stress Hypothesis*. This is a good model for unlike the previous example, here social context is readily acknowledged as playing a role however, psychiatry then immediately denies this causal role of social context by implying that the only reason a person reacts to their environment is because the person is vulnerable to start off with. Thus once again social and environmental contexts are neatly put in their place as inconsequential and the focus can, once again, return to psychiatry's biological explanations and solutions to the person's vulnerabilities. Many examples abound such as the effects of racism and the prevalence of schizophrenia as due to a lack of vitamin D:

*"Increased rates of psychosis found in darker-skinned migrants, who process vitamin D less efficiently due to the weak sunlight found in northern latitudes, may also reflect an association between vitamin D deficiency and psychotic symptoms."*<sup>106</sup>

Likewise trauma can be acknowledged, yet it is diverted back to a biogenetic explanation highlighting again that the focus is the problem, for psychiatry is not always denying environmental factors it just focuses on biological factors:

*"Discussed the relationship between childhood trauma, cognitive function and the BDNF Val66Met (rs6265) genotype. Using data from 249 young people with schizophrenia and bipolar disorder, she demonstrated that Met carriers (Val/Met or Met/Met) showed lower perception and visual ability, and executive function than Val/Val carriers."*<sup>107</sup>

Yet academic psychiatry is increasingly finding itself in a crisis by insisting on a reductionist interpretation of meaningful human behaviour as expressed in the newly released DSM 5 which is receiving critic from many sides. The director Thomas Insel of the prestigious National Institute for Mental Health (USA) distanced itself from the new DSM V as too unscientific stating:

*"The strength of each of the editions of DSM has been "reliability" – each edition has ensured that clinicians use the same terms in the same ways. The weakness is its lack of validity. [...] DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure. In the rest of medicine, this would be equivalent to creating diagnostic systems based on the nature of chest pain or the quality of fever." [...] "Patients with mental disorders deserve better."*<sup>108</sup>

Resulting in Chair of DSM-5 Task Force David Kupfer, MD declaring:

*"The promise of the science of mental disorders is great. In the future, we hope to be able to identify disorders using biological and genetic markers" [...] "Yet this promise, which we have anticipated since the 1970s, remains disappointingly distant. We've been telling patients for several decades that we are waiting for biomarkers. We're still waiting."*

This is in direct contradiction to years of stating mental distress is genetic in origin expressed as chemical imbalances in the brain. Shortly afterwards Insel, in a joint statement with the APA president elect hinted at what is at stake if e.g. postpsychiatry were to be a reality, appeared to recant asserting the DSM:

*"Represents the best information currently available for clinical diagnosis of mental disorders. Patients, families, and insurers can be confident that effective treatments are available and that the DSM is the key resource for delivering the best available care."*<sup>109</sup>

And

*"We were concerned that comments about how to move beyond some of our traditional, symptom-based methods of diagnosis -- which are, at the moment, the gold standard of science -- were widely misreported as NIMH changing its position on the newly revised DSM-5. This is, of course, a preposterous notion."*<sup>110</sup>

From a postmodern perspective, this would appear to indicate that psychiatry's success in the 1970s and 80s in introducing a monologue of reason underpinned by a modernist scientific ethos has; in postmodern times where access to multiple sources of contradicting knowledge, highlighted that its singular scientific fundament increasingly appears to be a belief rather than evidence based. Yet distressed people who have

adopted the language of psychiatry exist, indicating that illness -also that of the mind- as a concept, is multifaceted, existing for some but not for others.

This supports postpsychiatry's insistence that mental distress though real, is socially constructed and only by engaging with the distressed individuals in meaningful ways based on understanding and context will that ensure psychiatry is equipped to overcome its crisis. This must include the arena of medication from other perspectives than that of the dominant psychiatric discourse.

## CONCLUSION AND CLOSING DISCUSSION

My seven interviewees represent a cross section of current and former service users all diagnosed as schizophrenic. They allow a view of psychiatry from a postpsychiatric angle—a perspective that has largely been ignored in the scientific literature of psychiatry. The interviewees provide accounts of their own subjective medication experiences that clash with those of the dominant psychiatric discourse, which attempts to describe and control the experience of patients. The stories of the interviewees contradict the dominant psychiatric discourse that posits that medication is a necessity and largely helpful for those deemed psychotic. The interviewees' experiences seem consistent with much of the literature of postpsychiatry that argues that medication, especially long-term use of it, contributes to a paradigm of chronic illness and potential life-threatening side effects. The interviewees' experiences also seem to support the literature that increasingly shows that those who reduce or stop their medication have better global outcomes than those who continue to take medication.

Though it appears logical from a postpsychiatric and service-user perspective that user experience, including that of medication, should be of equal value in terms of knowledge production and negotiation, that is not yet the case. This thesis shows that if we are to involve patients on an equal footing with regard to their medication experiences we cannot ignore the context of their lives. It becomes clear, as demonstrated by my seven interviewees, that when we acknowledge their experiences, meaning and understanding emerge and madness ceases to be such a meaningless entity. This was clearly demonstrated by the profound roles some staff played as told by some of the interviewees. Postpsychiatry, by viewing distress from a multifaceted perspective and taking a more nuanced approach, is not trapped in a monologue of madness.

My interviewees reveal that psychiatry's preferred method for dealing with the discrepancies between psychiatry's medication experience and the interviewees' own is to symptomize or downplay their experiences, and one could extrapolate and posit that this is representative of those labeled schizophrenic in general. Treating patients' experiences as meaningful is profoundly threatening to the medical model of madness which is dependent on meaninglessness or the supposition that lived lives are of secondary importance. Indeed, the threat posed to the medical model by considering madness meaningful is overwhelming. It becomes clear why there is such resistance to acknowledging the discrepancy between psychiatry and service-user knowledge. There are many practices and realities in the psychiatric everyday involving power, contexts, meanings, science, help, crime and punishment, standards and norms, empowerment and disempowerment, and so forth, yet throughout it all, medication is the overriding theme permeating psychiatric everyday practices in a huge variety of guises. Its dominance means that

one can equate medication to the tree of psychiatric life or the glue that is currently holding psychiatry together.

I believe that this thesis hints at the crisis in which academic psychiatry finds itself and that it simultaneously contributes to postpsychiatry and the gathering momentum for a potential postpsychiatric era that Bracken & Thomas, HVN and others believe is a very real possibility in the future. Much is at stake, so there are and will continue to be turf wars. But if a tipping point is reached and the medication glue that holds psychiatry together becomes unstuck, an interesting future regarding mental distress lies ahead of us.

## ENDNOTES

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