

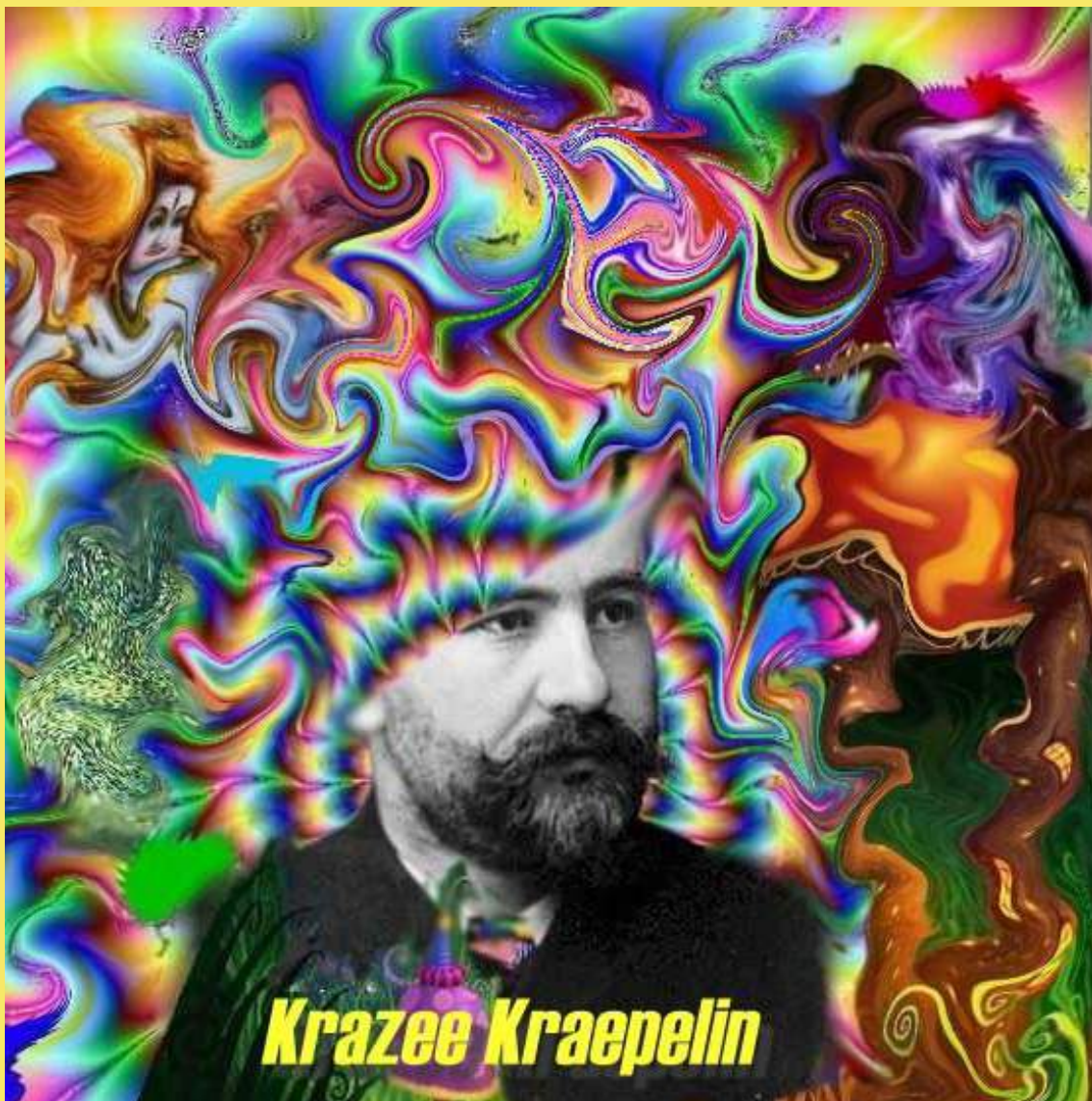
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SCHIZOPHRENIA

1911-2011

R.I.P



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EDITORIAL

SCHIZOPHRENIA 1911-2011 R.I.P?

It is one hundred years since an eminent psychiatrist published a book which announced an alarming kind of mental disorder - SCHIZOPHRENIA. This idea - the 'split mind' - brilliantly evoked the enigma of all those frightful psychoses which lack any apparent organic cause yet seem suddenly to afflict people in the prime of life. But whether 'split mind' is a disease, in the sense of it having an organic cause, was and remains pure speculation.

Perhaps this was psychiatry's greatest ever PR coup: seeming to identify a bogey which frightened the public, yet at the same time offering the hope of an assault upon this 'disease' by means of progress in scientific research upon its exact nature and in finding an antidote.

In the meantime, and although no organic cause has been discovered (and not for want of trying), the idea of schizophrenia caught on rapidly. It still grips the popular imagination. (And certainly the imagination of most psychiatrists. Or perhaps we should say: the lack of imagination of most psychiatrists.) The notion of a disease called schizophrenia is so compelling because most people wish that such apparently unaccountable psychoses were due to a real illness. Then the psychosis would be nothing to do with them, nothing they could do anything about, and best left to the doctors to 'manage' with medicine - just like any other illness that randomly afflicts the unlucky.

During the last century many have tried to locate that elusive organic cause. A bio-chemical quirk? A genetic glitch? A virus? Researchers are still looking.

However, quite a different idea about abnormal psychology happened to be emerging at the time of the celebrated 'discovery' of schizophrenia. This

alternative view argued that the best bet is that any functional mental disorder is due to the person suffering from psychological problems. (A functional mental disorder is one for which there is no clear organic cause. Most psychiatric cases are functional mental disorders. Misleadingly, they are known as 'mental illnesses'.)

And so, if only the psychiatrist were to adopt the right approach and take the time to find out, any psychosis in late adolescence or early maturity might be accountable enough in terms of psychologically traumatised emotional and mental development under very difficult circumstances.

As soon as it was proposed, a few of these dissenters did argue that the whole idea of the disease of schizophrenia was quite wrong. Nowadays probably a rather greater number of people (although still a small minority) argue that the diagnostic category has had its day. Despite a hundred years of research no organic cause has been found, and there is now much evidence that the origins of most psychoses are to be discovered in psychological trauma during childhood.

If there really is no such thing as a disease called schizophrenia, stigmatising people with that diagnosis and poor prognosis, and maltreating them with dangerous psychiatric chemicals, does absolutely nothing to help anyone understand what is going on - especially when the individual concerned is already overloaded with psychological and social problems. On the contrary, the diagnosis and the medical treatments are perilously obstructive to recovery.

The diagnosis of schizophrenia has blighted countless lives. Surely it is time to call it a day for this particular mythical disease?

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HOW PSYCHIATRY ARRIVED AT THE IDEA OF SCHIZOPHRENIA

Professor Alec Jenner

'Schizophrenia' is a well-worn word but it is questionable that it denotes any 'thing' – that is, any specific, identifiable disease. The term was coined by the Swiss psychiatrist, Eugen Bleuler. He came up with it in 1908 and it became widely known when he published his book in 1911. Those two Ancient greek syllables, *schizo* and *phrenia* are perhaps best translated as 'shattered' and 'mind' (although originally it referred to the abdomen, where some Ancient greeks thought the mind resided).

Towards the end of the 19th century, French psychiatry introduced the idea of *démence précoce*. And then, so as to establish a proper medical-scientific taxonomy, the Latin expression *dementia praecox* was suggested by the great german psychiatrist kraepelin, who worked hard trying to fully describe the symptoms. *démence précoce* and *dementia praecox* translate as 'precocious dementia', i.e., a dementia-like disorder, with onset well before dementia might be expected, that is, during late adolescence or early adulthood rather than in old age. The term 'schizophrenia' was introduced to replace dementia praecox, and it soon became more popular.

All these terms were an attempt to label an illness, but they included slightly different clusters of symptoms and prognoses. For Bleuler, the main problem was that *dementia praecox* implied an incurable disease, an irreversible organic dementia. And yet, during the early part of the 20th century it became clear that at least one-third of those with the diagnosis did actually recover.

Bleuler ran a psychiatric clinic in Zurich and was influenced to some extent by Jung, who was all for a psychological approach to understanding mental disorders. As his boss, Bleuler had encouraged Jung to go on leave so as to study with Sigmund Freud in Vienna. (Actually, Freud believed that schizophrenics were too estranged to be helped by psychoanalysis.) Initially, because he could not be sure they related to one specific disease, Bleuler used the term to refer to a collection of abnormal mental states – hence he used the plural: *die schizoprenien*, i.e., *the schizophrenias*.

Unfortunately, Bleuler lost his original optimism. For example, Nijinsky was probably the most celebrated male ballet dancer in the world. After a stressful decade, in 1919 he had a breakdown. He was sent to the Zurich clinic and Bleuler informed his desperate wife that little could be done due to his schizophrenia. So Nijinsky got little help and spent the remaining thirty years of his life in and out of psychiatric units.

By then Bleuler had also long given up using the plural form of the word. It is now universally used in the singular. However, this is probably a mistake because to do so makes 'schizophrenia' seem like a homogeneous and concrete thing (an actual constitutional disease) and not just a psychiatric category that is simply a tentative step towards a more useful classificatory vocabulary.

kraepelin's general outlook still remains dominant in the minds of most psychiatrists. Central was his distinction between manic-depressive psychosis (now known as bipolar

disorder) and schizophrenia. more modern work also shows very different responses to different drugs by those diagnosed. And yet at post-mortem the brains of those diagnosed with bipolar illness and schizophrenia show no clear differences at all, or differences from those of people considered mentally normal. Hence both conditions are generally considered *functional disorders*. This distinguishes them from psychoses which are undoubtedly organic, such as senile dementia and cerebral syphilis (general Paralysis of the Insane).

In fact, syphilis was very common when kraepelin was writing, and remained so until penicillin was discovered. So this experience of real organic brain disorders heavily influenced psychiatric thinking. Kraepelin is often ridiculed by modern anti-psychiatrists. Of course much of what he thought was incorrect and based in the perspective of his time – particularly, in much of contemporary german psychiatry, a strong presumption of an organic basis to the major mental disorders. Difficulties distinguishing some obviously physical diseases from the psychological disorder of schizophrenia made a physical explanation of schizophrenia seem likely. However, kraepelin genuinely struggled to get things right, and his humility is striking. His original work was based simply on the signs and symptoms presented by his patients. When a reliable physical test became available for the diagnosis of syphilis (the Wasserman reaction) kraepelin realised how often he had mistaken the diagnoses, in both directions. Even in distinguishing manic-depressive from schizophrenic patients, he admitted that he had been too dogmatic. many of us with very confident views on psychological matters could learn a lot from kraepelin.

What remains of kraepelin's great work on schizophrenia? Some might argue nothing at all, since, as a real disease (an organic, genetic or chemical condition) there is no such thing as schizophrenia. So we need another word. Why not, if you want one? If you just change a word, though, you have changed very little. Nevertheless words are important, especially if, for example, they limit our attempts to understand what is going on.

later, the german psychiatrist, Schneider became very influential when he 'tidied up' the diagnosis of schizophrenia by recommending a series of what he called 'first-rank symptoms'. This list includes: hearing voices; speaking about oneself in the third person ('he' or 'she' instead of 'I' and 'me'); being convinced that one's thoughts are being broadcast; believing one's movements are controlled by outside forces; and believing that strange thoughts are being injected into one's mind. karl Jaspers suggested that a diagnosis of schizophrenia must depend on whether or not the person is understandable (for example, as when we can understand characters when we read a novel or go to a play).

However, all this focus on getting the diagnosis right meant that most psychiatrists were left still trying to explain schizophrenia in the language of physics and chemistry rather than in that of developmental psychology.

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emails from Georgie Paul Hammersley

From: georgie
 To: mum
 Subject – Excited!!!

Dear mum

It's my first week at university and I'm very excited. It's all a bit new but people seem friendly. As you know I'm not the world's best 'friend-maker', especially after all the things that happened. The two girls next to me in my hall have said hello. First lecture tomorrow, so I'm having an early night. I've put a picture of Archie on my wall to make me feel at home, and I'm going to snuggle up in my new duvet!!

I hope I have made you proud; I'm going to be a lawyer and a big success.

It's very hectic, so I'm keeping a low profile and working hard, the people here are very different to what I'm used to. I've joined the hiking club, some fresh air will sort me out, things are Ok but I'm quite home-sick.

I miss you and Archie, but I'm going to be strong
 IOI to everyone

georgie xxx

From: georgie
 To: mum
 Subject – Sorry

Hi mum

Sorry about the phone call the other night, I was very upset and I can't remember some of the things I said, but I reckon they weren't good.

Any way, here is the good news, I spoke to my tutor as you advised. He sent me to the University counsellors who have decided that I need to see a consultant psychiatrist who can get to the bottom of this and give me the help I need.

Thank god. Sorry for being a pain, but this can get sorted out now, good news at last.

IOI georgie

From: georgie
 To: mum
 Subject – Why?

You fucking bitch!! Why have you done this to me? What did you say at that fucking tribunal, I'm on a section three; I'm going too stuck in this hell hole forever.

I'm scared and I can't think straight, the voices from the TV laugh at me all day, and I've put on two stone in weight.

They say I've got schizophrenia; the social worker wants me to do some part time voluntary work to build up my confidence. I wanted to be a lawyer.

Please get me out of here, I can't cope, no one contacts me and I'm losing track of time.

Please mum help me

georgie

From: georgie
 To: mum
 Subject – I've tried ☹

Dear mum

I am so sorry to do this to you, but I can't go on anymore, this brain disease has beaten me.

You looked after granddad for years, but not me as well. I'm not putting you through it again.

I don't know why it turned out like this; I used to be so happy.

Anyway, I've run out of reasons to stay alive so tonight's the night. I've thought it all through and it won't hurt.

Pick a 'Take That' song for the funeral (if anyone turns up,) we used to dance to them, remember?

I hope they can find a new treatment for schizophrenia, because this one certainly didn't work for me.

love you forever See you in Heaven

georgie xx

From: georgie
 To: mum
 Subject –Wow!!

Dear mum

It's not going that well, but I think I'm coping!!
 I'm not sleeping properly (as usual) and I've missed a few lectures. I can catch up though; I work at night when it's quiet.

making friends has been hard; I get nervous around new people and I've got to do a presentation soon, which is a total stress out. I was going to get some sleeping tablets from the doctor just for a few days, but the boyfriend of one of the girls in my class says he can get me something to make me sleep, he seems nice so I'll go with that.

How is everyone? Is granddad still a bit dizzy?
 I luv you all and will be home and fine at Xmas.

georgie

From: georgie
 To: mum
 Subject – Progress

Dear mum

The psychiatrist was very reassuring,
 He explained to me that I have a chemical imbalance in my brain, which makes me hear things from the television. It's all to do with chemistry and genetics, I didn't quite understand (I always was crap at science) and anyway my new medication makes it hard to concentrate, but it does calm me down I'm going to go into hospital (only for a month) so that I can have a rest and let them do the tests. This is exactly what I need.

love you all
 georgie

From: georgie
 To: mum
 Subject – New address

Hi mum

I'm so sorry about the last email.
 I'm in the new place now and I get a lot of help from a student social worker called Becky, she's leaving soon which is a shame. We go swimming every week, but I can't lose this weight, none of my old clothes fit anymore. I might take up smoking, it's the main event round here (only joking)
 The telly keeps on chatting away, but it's not as loud which is a blessing. I haven't really got anyone to talk to, but then again I was always shy, so no difference there.
 I've had another medication increase, perhaps that will do the trick.

love you

georgie

SCHIZOPHRENIA: myth & reality

Phil
Virden

The image of the most awful, chronic and incurable disease of schizophrenia is generally taken for granted. To say 'schizophrenia' is to collect under one rubric all the signs of the truly mad. The schizophrenic is supposed irremediably to inhabit a mental space completely at odds with that of the sane. The bible of world psychiatry, *the diagnostic and statistical manual* (DSM), lists the symptoms: 'strange activity'; 'lack of guile'; ideas of one's own special significance (or special insignificance); disregard for others; reported hallucinations; paranoia; sometimes catatonia.¹

All the authorities agree that about 1% of the world's population suffers from this terrible 'illness'.² If so, about one family in twenty or twenty-five must be directly affected. Naturally, much psychiatric research has been concerned with solving the conundrum of this most disturbing and perplexing condition. However, there is absolutely no evidence that there is an organic cause for schizophrenia – which is to say, that it is really an illness at all.

The distinction between real illnesses and overwhelming psychological problems

There is a distinction between real illnesses which have undesirable mental effects and so-called 'mental illnesses' for which there is apparently no organic cause: these are the functional mental disorders, popularly known as 'mental illnesses'. Although there are often certain somatic correlates with these mental disorders (heightened arousal, etc.), there is no evidence for any organic cause: they are disabling psychological states. And they make up the bulk of the mental health and psychiatric caseload. Strictly speaking, these 'mental illnesses' are not illnesses at all.

So, on the one hand there are real (organic, neurological or brain) diseases which have unfortunate mental or mood effects; these include senile dementia, meningitis, brain degeneration due to untreated syphilis, etc., and some brain injuries. On the other hand, there are the functional mental disorders, for which there are no organic causes. Despite 150 years of medical research, there is no evidence of any genetic, infectious or bio-chemical cause for any functional mental disorder. Hence the distinction: with a functional mental disorder, the person is well enough but he does not function well enough. (Psychiatrists assume that it is the brain that does not function properly. But there is no evidence for this, and actually it is the person whose functioning is worryingly aberrant.)

Of the functional mental disorders, a practical distinction is made between neuroses and psychoses. The neurotic is or can become aware of his disabling mental, emotional, motivational or behavioural problems, and usually wishes to remedy them. The psychotic clearly has such problems, and usually in a more extreme degree, but he does not acknowledge them, and hence, generally, has no wish to remedy them. The emergence of the notion of 'schizophrenia' was the medical attempt to understand and manage serious and intractable psychoses. That is to say, it is the attempt to comprehend and remedy medically what is not actually a disease but a psychological condition. This is why the whole notion of 'the disease of schizophrenia', and its medical treatment, is profoundly suspect.

Schizophrenia timeline

In 1857, B. A. Morel identified a process of severe intellectual deterioration beginning at puberty. He called it *démence précoce* (precocious dementia).³ 'De-mentia' translates literally as 'out of' or 'without mind'; this was already only medical jargon for 'madness' or 'feeble-mindedness'. *Démence précoce* is therefore a chronic and deteriorating psychotic disorder characterised by rapid cognitive disintegration and usually starting in late teens or early adulthood. 'Cognitive disintegration' refers to disruption in mental functioning, such as perception, attention, memory, and goal-directed behaviour.

By the 1880s, three other kinds of psychoses were recognised: *hebephrenia*, by disorganised speech and behaviour and 'flat' or 'inappropriate' emotion; catatonia, by psychological and motorological disturbances – often obsessive rigidity, 'waxy flexibility' or repetitive movements; and dementia paranoides. In 1893 E. Kraepelin refined and further defined the idea of one chronic degenerative disease by bracketing together the syndromes of *démence précoce*, *hebephrenia*, *catatonia* and *dementia paranoides*. He called them 'the psychological degeneration processes'.

In 1899 Kraepelin decided that these syndromes comprise one disease. He distinguished psychoses with a good prognosis (tending to remission), which he called manic-depressive, from those which begin early in life, tend to progress and have a poor prognosis, which he called *dementia praecox*. It seemed to him that the primary disturbance in *dementia praecox* is that of thinking or cognition, whereas manic-depression is a disturbance of mood. Kraepelin vividly and exhaustively described the symptoms of *dementia praecox*: hallucinations, delusions, characteristic apathy and/or busy but ineffective and grossly inappropriate volition and expression, the dereliction of the patient's social graces and personal hygiene, etc.⁴

In 1911, E. Bleuler proposed a group of mental disorders which share some features and all show a particular type of thinking, feeling and relating to the world which these days would be called 'autistic'. In order to refer to the 'splitting' of mental processes, characterised in one symptom-complex (or syndrome) of what he thought was one type of chronic degenerative illness, he called them 'the schizophrenias' – from the Greek, meaning 'split mind'.⁵ During the next thirty years psychiatrists came to favour the diagnostic term 'schizophrenia' rather than '*dementia praecox*'.

And in 1955, K. Schneider 'polished-up' Kraepelin's work by describing the 'clear signs and symptoms of schizophrenia'.⁶

Diagnosing schizophrenia today

Since the late-1950s psychiatrists have agreed that schizophrenia is clearly signalled by the presence of one or more of Schneider's first-rank symptoms.⁷ These are:

- hallucinations – auditory are by far the most frequently reported;
- interference in thinking – ideas that other agencies are putting thoughts into the person's mind or extracting or

broadcasting his thoughts;

- passivity experiences – strange body-experiences, including notions that it is invaded by alien objects and that the person's actions are not self-willed;
- delusions – bizarre non-consensual beliefs, generally including ideas of persecution.

Apart from these positive first-rank symptoms, psychiatrists nowadays also employ two further criteria:

- thought disorder – attributed when the psychiatrist cannot follow what the suspected schizophrenic says: loose association, concreteness, over-inclusiveness, paralogical (illogical) thinking;
- catatonia – marked behavioural disorganisation.

During the last thirty years or so psychiatrists also became interested in 'the negative signs' of schizophrenia – with what seems to be missing from the personality. These include:

- blunted affect – an apparent lack of emotion;
- poverty of speech – where the person says very little or gives little away;
- lack of drive, pleasure or attention.⁸

These 'negative signs' seem equally applicable to someone simply in a state of depression or apathy. And they might well be specific to certain situations, making them easily comprehensible as forms of fairly rational retreat from situations – or other people – that the person cannot otherwise avoid, such as members of his family or insistent psychiatric workers.

Negative signs usually seem to emerge slowly. They also tend to fail to respond to neuroleptic drugging. However, the positive symptoms generally emerge suddenly and do sometimes tend to abate with the use of neuroleptics: to the medically minded, this makes them appear the clear symptoms of a specific disease.

An early critique of the medical prejudice

The term 'schizophrenia' only replaced '*dementia praecox*'. It did not add any new ideas or information to the notion of what almost every psychiatrist supposed was a real (organic) disease. When this new name was introduced, Emile Kraepelin was the great international authority to whom every other psychiatrist deferred. And yet

Kraepelin ... only offers us a general and superficial view of the disease ... [He] makes no attempt to explain the senseless utterances and actions [of his patients]. In other words, whereas he gives us an accurate, almost photographic representation of the patient's general behaviour, he does not enter into his psychological productions. He contents himself with noting that the patient entertains such and such hallucinations and delusions, and such and such mannerisms, without examining the causal relations. [Yet] those who work among the insane know that no two cases of *dementia praecox* [schizophrenia] are alike; there is always a difference in the grouping and

relationship of the symptoms, every case having its own individuality. Kraepelin, like his predecessors, totally ignores individual psychology, a thing absolutely essential for the understanding of the psychosis ...⁹

Medical dogma and the self-fulfilling prophecy

Nobody becomes a psychiatrist without first of all training for years in general medicine. This predisposes psychiatrists to a medical prejudice whenever they confront psychological or emotional problems: every doctor's reflex is to see every complaint as essentially an illness. And so he assumes it requires medical diagnosis, prognosis and treatment. Surely, anything else would be irresponsible?

And ever since the time of Kraepelin and Bleuler, psychiatry has generally given diagnosed schizophrenics little cause for hope. (Although in later years both did allow that perhaps not every case was completely hopeless.) But if one believes that a person undergoing a psychosis suffers from a degenerative disease for which the cause is yet unknown and for which there is no known remedy, then of course there is little hope. And, one hundred years on, this is still the case: if they decide that he 'has' schizophrenia, psychiatrists still tell the patient and his family and friends that 'it is genetic' or 'a bio-chemical imbalance', that there is little hope of recovery, and that he will probably have to keep taking the drugs for the rest of his life.

However, from the earliest days, there were those who questioned the consensus because there was simply no evidence to support any medical hypothesis and, besides, psychodynamic theory provided a perfectly plausible alternative. For instance, despite Freud's pessimism about remedying psychoses, Carl Jung was a practicing psychiatrist when, as early as 1906, he urged the psychoanalytic point of view: every case of *dementia praecox* (schizophrenia) should be viewed as the culmination of a desperate psychological adaptation to unresolved, overpowering emotional and mental trauma during the individual's earliest years.¹⁰

Besides, statistical studies refute the poor prognosis of orthodoxy. By the 1980s, every study anywhere in the world which had followed diagnosed schizophrenics for at least twenty-five years had discovered that, by any criteria, about 35% fully recover and another 35% function independently and are self-supporting but with some residual symptoms.¹¹ Moreover, this is not the result of modern medication. In Switzerland, where the diagnosis of schizophrenia was first used and where there are accurate population records since about 1900, this generally benign course of the malaise has been true ever since the diagnostic category was devised.

A bad prognosis too easily becomes a self-fulfilling prophecy. No good is expected of the patient, all that is on offer is stigma, prejudice, discrimination, drugs with frightening 'side effects', and inadequate emotional, conversational and material help – and so of course he fails to recover. So far as Thomas Szasz is concerned, what is chronic is not the fictional disease but certain social expectations – especially those of families, doctors and psychiatric workers. There is plenty of cogent sociological argument and some enterprising social research to indicate that, because everyone's expectations are set like stone in the institutional arrangements of psychiatry, once someone is embarked on a career as a mental patient it is very difficult for him to disembark.

...[W]hereas the term 'bodily illness' refers to physico-

chemical occurrences that are not affected by being made public, the term 'mental illness' refers to psycho-social events that are crucially affected by being made public.¹²

Medical research into the cause/s of schizophrenia

The purported discovery of schizophrenia was not at all the result of medical research but only a motivated tautology: over-zealous psychiatrists wished so much that there was a real disease which they could treat medically. The so-said discovery was never more than the *proposition* of a syndrome: because they *wished* it were so, influential psychiatrists gathered together the various signs and simply *asserted* that they constitute the symptoms of one particular disease.

In fact, despite a century of determined investigation, no organic cause of schizophrenic behaviour has ever come to light: apparently there is no genetic, bio-chemical or infectious agent. For example, it is true that there is some tendency for schizophrenia to 'run in the family'. But the proponents of geneticism always fail to allow that this may be explained by good evidence that a child in a family in which a significant other is psychotic is more likely to experience a mentally traumatising degree of material, emotional and cognitive deprivation, confusion and deprecating indoctrination, if not outright oppression. It is also known that pre- and ante-natal physical development (including that of the brain) is inhibited by nutritional deficiencies or by the mother experiencing chronic stress, or by heavy use of narcotics, alcohol or tobacco – all of which also tend to 'run in families' containing someone diagnosed with a serious mental disorder. Over the years there have been a number of false claims, but no 'schizophrenia gene' has been discovered.¹³

Schizophrenia is a mythical illness

In fact, nobody has been able to demonstrate that Schneider's set of defining symptoms apply only and exclusively to those particular patients diagnosed as schizophrenic. The first-rank symptoms *are very often* also found in patients who suffer from other types of psychosis. All that can safely be said is that someone attracts the diagnosis if he begins to live in a more or less permanent state of emotional turmoil and shows certain seriously worrying signs of mental disturbance, especially when interacting with people he sees as threatening.

There is not one disease – schizophrenia – which some individuals are simply unfortunate enough to 'contract' or 'develop' out of some genetic or bio-chemical predisposition. Whilst there are certainly people who suffer from a psychosis, nobody ever 'has' the disease of schizophrenia. Like griffins and dragons, schizophrenia is only a mythical entity, imagined by those blinded by medical prejudice.

But if schizophrenia is not a real illness, what is going on?

This question was addressed by psychoanalytically inclined psychiatrists and theoreticians as soon as the notions of *dementia praecox* and schizophrenia were proposed. And now common sense and the law (but not yet mainstream psychiatry) is catching on to the theory of psychological trauma.

All 'mental illness' is post-traumatic stress disorder

Schizophrenia cannot be understood without understanding despair ... The experience and behaviour

that gets labelled schizophrenic is a special strategy that a person invents in order to live in an unliveable situation. R D Laing¹⁴

In the last quarter of a century or so it has become widely acknowledged that anyone who suddenly exhibits a chronically disabling emotional or psychological reaction to the experience of warfare, a terrible accident, a bombing or any other obviously horrific natural or man-made disaster, suffers from a post-traumatic stress disorder, *even in the absence of any organic injury*.¹⁵ Such an individual is entitled to compassion, counselling and often substantial financial compensation.

And by now it seems clear enough that the cause of any behaviour diagnosed as a functional mental illness will never be discovered as a physical lesion, aberration or disease of the brain. Rather, the first bet should be that it is a very distressed and confused state of mind resulting from some profound emotional or psychological trauma, as yet undisclosed. A mental disorder is any emotional or psychological condition experienced as intolerable or disabling; it is a type of post-traumatic stress disorder – the response of the individual panicked by overwhelming anxiety.

An officially recognised functional mental disorder is usually precipitated by the added burden of a current personal crisis on top of a high level of long-term anxiety engendered by secret or unacknowledged conflicts, disasters or horrors experienced by the individual, usually beginning during childhood. When it becomes more or less a fixed condition, the mental disorder consists in the person's imaginative yet aberrant accommodation to his ongoing anxiety. And when it precludes the person from acting in an acceptable or safe manner, and is accompanied by the requisite 'symptoms', it is this apparently fixed condition which doctors call 'the disease of schizophrenia'.

In which case, the same sort of compassion and help which is offered to a person suffering from what is now acknowledged as a Post-Traumatic Stress Disorder (PTSD) should be extended to the patient who suffers from what is still viewed a functional mental disorder. And it would help if we stopped thinking of those diagnosed with 'a mental illness' as actually ill. They are not: they have specific psychological problems resulting from specific overwhelming problems in their lives.

At the moment, PTSD is attributed to those who rationally report recurrent, too vivid and frightening memories ('flashbacks') of the experience of a traumatic event; the trauma is publicly acknowledged and generally happens to the subject after childhood. This distinguishes that form of PTSD which is officially ratified, researched and treated by psychologists and psychiatrists from the far greater number of disabling responses to lasting and disabling emotional trauma which are presently known as 'cases of mental illness'. Today, and for the last century or so, the notion of 'mental illness' is employed for all those forms of post-traumatic stress disorder in which the subject apparently cannot remember, or cannot or will not articulate a memory of a trauma, or is not believed when he does recall it: the trauma goes unrecognised, either by the subject (who actively represses or is unable to speak of his traumatic experience) or by the public and those officials who define his mental and emotional condition.

Irrational psychological accommodation to overbearing

anxiety is, in fact, extremely common. So long as many people share an anxiety, the imaginative accommodation to it often takes an entirely acceptable form as an element of the general culture or ideology. Many points of religious dogma are irrational – and they tend to be the beliefs which are most fiercely defended. Yet there are also many secular beliefs that are both widely held and irrational. Amongst other ill-founded dogmas about personal and social formations is blind faith in 'the medical model' of functional mental disorder and the efficacy of standard mental health and psychiatric treatments. For example, people tend to be very anxious about individual irrationality and would prefer a doctor to deal with it. Hence the medically unfounded belief that schizophrenia is a disease and that the afflicted person can do little more than keep taking anti-psychotics for the rest of his life.

With respect to longer-term suffering, and caused by any terrifying circumstances, Judith Herman pushed for the recognition of a condition she calls complex post-traumatic stress disorder (CPTSD). This is 'the syndrome that follows upon prolonged, repeated trauma'; it is psychological injury due to 'protracted exposure to prolonged social and/or interpersonal trauma with lack or loss of control, disempowerment, and in the context of either captivity or entrapment, i.e., the lack of a viable escape route for the victim.'¹⁶ Outside of war, the main sources of trauma are physical, sexual and emotional violations or abuse, and mainly experienced during childhood.

The crisis of psychosis

Eighty years ago, Hans Selye began to explore the hormonal and behavioural effects of stress upon both animals and humans.¹⁷ Sixty years ago, Aldous Huxley showed how psychosis may be induced by over-stressing the body and inducing hormonal changes.¹⁸ And the famously 'hard-nosed' champion of medical psychiatry, William Sargant, wrote about the possibilities of 'breaking-down' people by means of fear and extreme stress (that is, inducing a psychosis) and then 'brainwashing' them with a new set of beliefs (delusions).¹⁹ Psychiatry has paid no attention to these ideas, but others are now persuaded that the cause of any psychosis is trauma and overwhelming stress. The trigger might sometimes seem to be a hallucinogenic drug or alcohol, but this simply begs the question of the traumatised and stressful context of the person's life.

Consider the symptoms of schizophrenia. Whilst apathy is the renunciation of the self, in defeat, mania is the further reach of grandiosity – wherein the person is overwhelmed by the notion of his own great significance. Psychoanalytically, mania arises from disturbed narcissism within an individualising and competitive culture. As a defence against actual threats and confusions, and in denial of private terror and panic, it is an egocentric and grandiose view of the self, a process of pride or expansion of the ego expressed in a conviction of great personal power or some imaginary achievement or potentiality which will raise the person up from low social- and self-estimation to a position of great value and recognition. The person keeps buzzing by the combination of unrelieved anxiety and euphoria from the idea which denies the anxiety and boosts his self-esteem. Hyperactivity is a form of denial – the attempt to block-out depressive ruminations by constant activity.

This explains the clinical diagnosis of manic-depression

or bi-polar disorder: alternating assertion or apathy, denial or acceptance of defeat. We talk about 'nervous breakdown', and employ popular psychiatric terms like 'schizophrenia' with regard to anyone who enters the upward spiral of mania. This is the sequence: under current stress, suddenly intolerable anxiety > fretful denial of the grounds for the anxiety and confused preoccupation with self-worth > escape by entering into hyperactivity > insomnia and exhaustion > increased anxiety, panic, preoccupation, denial and flight > increased insomnia and exhaustion > derealisation and hallucination (psychosis).

Unfortunate events are more likely to happen to someone, or are triggered by his abnormal behaviour, when due to stress and exhaustion he loses his reasonable grip on both internal and external realities – when he is already confused, distressed and incapacitated. This disability only deepens the individual's confusion, distress and incapacity. As he loses touch with reality he loses confidence in his perceptions about what is going on within him and around him, about what is being caused by him and what is being said and done to him. Rising anxiety fuels his paranoia, and the movement into psychotic crisis accelerates. As his anxiety rises, the individual is likely to deny the distress or the precipitating traumatic cause in order not to have to accept and face his own increasing distress, confusion and incapacity, which is itself anxiety-making. Delusions are constructed so as to defend the person against his anxiety and yet supply a (bizarre) sense of coherence, identity and self-esteem.

The therapeutic key to this sequence is exhaustion. Whatever the other difficulties, it is not possible to allay any of the underlying anxiety until the individual is relieved of his exhaustion by sound enough sleep, facilitated by an atmosphere of reassuring inclusion and security, and either by giving whatever time it takes to 'talk him down' or by the quick route of sedation.

It seems that every child normally makes an imaginative retreat into fantasy in order to deny, avoid and escape whatever he finds too painful to bear. Whereas this is transparent in a child's behaviour, the mental process working to produce the delusions which sustain a psychosis are hidden behind the rationalisations of an older person who, as part of growing up, learns to become more successfully private and secretive. However, at any age, as the imagination loses touch with the real world, fantasy fills more of the mental space, and the boundary between reality and fantasy becomes increasingly blurred.

In more serious exercises of defensive self-persuasion this boundary disappears: the urgency of the emotional pain and anxiety translates into the fervour of the wish which, in turn, determines the depth and duration of the retreat into fantasy. The child already learns to construct his reality when he learns to speak. If much of what he imagines remains conditioned by what he wishes rather than by what is real (which is intolerably traumatic), and if his emotional distress (anxiety) meanwhile persists, this lays the foundations in childhood for a psychodynamic which manifests in adolescence or maturity – when those around him demand that he take up adult responsibilities – as a more or less preoccupying neurosis or a full-blown psychosis. For example, it is common for someone undergoing a psychosis to announce a delusion about the removal or substitution of his insides. Psychoanalysis explains this as the primal anxiety for the integrity of the person: 'the

removal of one's insides' is an abreaction in fantasy. For the sake of coherence, this *has to be accompanied by a reaction-formation* – a delusion, a hallucination or hysteria: 'my inside (myself) is not corruptible and dirty but empty/pure/a machine/a bag of stones, etc'.

'Schizophrenia' – that is, apparently profound and relatively long-lasting psychosis, often with onset in later adolescence or early adult life – is best understood as the self's struggle for coherence and a benign identity under the condition of its negation by the significant others. It is a process of social and psychic interaction, not a disease or genetic kink incubating within the individual. It seems to begin – which is to say, it makes its public appearance – as the individual's panicked response to stress within a general context of chronic over-repression. That is, where there is too much unrelieved threat, denigration and denial, and probably a lifetime of insecure over-dependence and anxiety. It results from the routine invalidation of the person's experiences, thoughts and feelings – his abuse or negation – at the hands of his most significant others. This causes problems for the individual's sense of himself and his world, prevents him from developing confidence and autonomy, and encourages him to retreat into fantasy.

In the absence of evidence to the contrary, we should investigate the hypothesis that any mental disorder is the response of an ordinary person – someone whose brain functions well enough, someone who is intellectually capable – to extraordinarily traumatic circumstances. The symptom is best understood as the outcome of a social, emotional, mental and somatic dynamic which is likely to have developed for years before the onset of the visible crisis. To be precise, the most plausible hypothesis is Freud's basic idea: as the response to emotional trauma, the foundations to every individual psychodynamic are laid down during the person's earliest years, and troubling events later in his life arouse the original anxiety and precipitate the crisis.

Endnote

No space to enter into questions of therapy, except to say that whilst drugs may have a temporary utility, to think of psychosis as a medical problem (an illness) requiring only a blanket medical solution simply masks and makes chronic the person's real problems. It is obstructive to insist that social-psychological or biographical problems are medical ones: they need teasing out, case by unique case. For the immediate crisis what the person needs is respite – safety and sleep. After that, he needs to feel genuinely respected and included, and to be given as much material, emotional and intellectual succour as is necessary to bring him back into the community of the less irrational.

The information and ideas expressed in this article are expanded and evidenced in: Phil Virden et al., *psychiatry – the alternative textbook*, Asylum Books, 2010, especially in Chapters 11, 18 and 22.

Notes

1. See *the diagnostic and statistical manual, dsm-iv*, American Psychiatric Assn., 1994, pp. 285–6.
2. See I. Bird: *The Fundamental Facts: All the latest facts and figures on mental illness*, The Mental Health Foundation, 1999, and *report on mental health*, World Health Organisation, 2001.
3. B. A. Morel: *Le raité des dégénérescences physiques, intellectuelles et morales de l'espèce humaine*. Paris, Masson, 1857.
4. See E. Kraepelin: *dementia praecox and paraphrenia*, Livingstone, 1919.
5. E. Bleuler: *dementia praecox, or the group of schizophrenias* (1911), International Universities Press, NY, 1950. See also D. Hill: *the politics of schizophrenia; psychiatric oppression in the United States*, University of America Press, London, 1983, and M. Boyle: *Schizophrenia: A Scientific Delusion?*, Routledge, 1990, pp. 42–118. Both give excellent critical reviews of the development of the concept of schizophrenia, from its origins until its latest definitive form in *dsm-iii*, in 1980.
6. K. Schneider: *Clinical psychopathology*, Grune and Stratton (1955), 1959.
7. See K. Schneider: 'Primary and secondary symptoms in schizophrenia', in S. R. Hirsch and M. Shepherd (eds.): *themes and variations in European psychiatry*, J. Wright, 1974.
8. See P. Thomas: *the dialectics of schizophrenia*, Free Association Books, 1997, Chapter 1, pp. 11–25, for a discussion of these diagnostic categories.
9. F. Peterson and A. A. Brill: 'Translators' Introduction' to C. G. Jung: *the psychology of dementia praecox*, Journal of Mental & Nervous Diseases Publishing Co., NY, 1909, pp. v–vi.
10. C. Jung: 'The Psychology of Dementia Praecox', (1906), *Collected works*, Routledge and Kegan Paul, 1953.
11. See B. P. Karon's 'Introduction' to J. Modrow: *how to become a schizophrenic*, Apollon Press, Everett, (1992), 1995, p. xi.
12. T. Szasz: 'The myth of mental illness', *American Psychologist*, 15, 1960, pp. 113. For the sociological arguments and evidence, see P. Virden et al: *psychiatry – the alternative textbook*, Asylum Books, 2010, Ch. 14.
13. No space to argue this point here. For the research evidence, see P. Virden, *Ibid.*, Ch. 11 and its Appendix.
14. R. D. Laing: *the divided self: an existential study in sanity and madness* (1959), Penguin, 1965, and R. D. Laing: *the politics of experience & the bird of paradise*, Penguin, 1967, Ch. 5.
15. The diagnostic category PTSD first appeared in *dsm-iii*, American Psychiatric Association, 1980.
16. J. I. Herman: *trauma and recovery: the aftermath of violence – from domestic abuse to political terror*, (1992) Basic Books, 1997.
17. H. Selye: *stress in health and disease*, Butterworths, 1976.
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Split

Eleanor Longden

Schizophrenia, dissociation and the shattered self

Consider the following case example. It was written by an august and respected psychiatrist, revelling at the height of his professional powers, as he attempted to capture the agonised afflictions of some newly referred patients:

... The personality falls to pieces. These fragments can then exist side by side and alternately dominate the main part of the personality, the conscious part of the patient. However, the patient may also become a definitely different person from a certain moment onwards ... Thus we have here two different personalities operating side by side ... When the patients think of themselves as different persons, they utilise a correspondingly different tone of voice ... the patient appears to be split into as many different personalities as they have complexes.¹

Given its emphasis on psychological fragmentation, disintegration and disconnection, we might be forgiven for assuming this is an account of dissociative identity disorder (DID), a condition characterised by disparate, split-off personality states and a well-established response to serious and prolonged trauma. But it is not. The year is 1911 and the psychiatrist is Eugen Bleuler, chronicling his exploration of a mysterious new 'biological' entity: schizophrenia.

The evolution of the Split Mind

Like psychiatry itself, schizophrenia was born, bred and nurtured within the asylums of 19th century Europe. It was within these grim, sprawling institutions that Bleuler first established the concept in order to describe his most disturbed patients. Bleuler's clinical notes particularly emphasise the 'splitting' of psychological functions in schizophrenia. According to him this is the key impairment, characterising the condition and the inspiration for its name – from the Greek *schizein* (σχίζειν, 'to split') and *phrēn* (φρήν, 'mind').

Despite this etymology, schizophrenia is diagnostically distinct from DID (previously known as 'multiple personality disorder'), although the two have remained conflated in the public mind. Yet despite their current separation within clinical thought, psychosis and dissociation were not always independent concepts. In the late 19th and early 20th century, numerous psychiatric authorities used dissociative mechanisms to interpret psychotic 'symptoms' – tentatively, the understanding of functional psychoses/schizophrenia and hysteria/dissociative conditions began to converge.

For example, Charcot not only hinted at possible

connections between hearing voices and hysteria (conceptualised as dissociation-based) but also hypothesised its traumatic origin.² At the same time, Janet deemed acute psychosis a dissociative condition related to the expression of unconscious emotions, wherein traumatic memories that cannot be mentally and emotionally assimilated become 'split off' and operate subconsciously and autonomously from ordinary consciousness.³ In his formative text on hypnotism (induced dissociation) Forel observed that: 'one can produce many phenomena (hallucinations, false beliefs, memory deceptions ...) in the hypnotised which are also to be observed in the insane.'⁴

When expounding the nature of hysteria, Freud exploited Janet's thinking on dissociation and pursued an early theory suggesting its genesis lay in childhood sexual abuse.⁵ As early as 1865, Moreau de Tours had recognised that more elaborate manifestations of psychosis, characterised by hearing voices, bizarre beliefs and depersonalisation, was precipitated by intense stress.⁶

Although Kraepelin's notion of *dementia praecox* did not explicitly incorporate dissociation, many of his contemporaries maintained that dissociation-like processes were crucial to its aetiology and argued fiercely for the relevance of dissociative metaphors such as 'ego-fragmentation' and 'dissolution of self-experience'. For example, Stransky's notion of *intrapsychic ataxia* emphasised dissociation between intellectual and affective domains,⁷ and Jung drew unequivocal links with dissociation in *The Psychology of Dementia Praecox*.⁸

Even Bleuler himself, an enthusiastic advocate for the biological origins of schizophrenia, conceded that personal vulnerabilities interacting with external precipitants might help explain this new entity: '[A]fter careful analysis, we had to pose the question whether we are not merely dealing with the effect of a particularly powerful psychological trauma on a very sensitive person rather than with a disease in the narrow sense of the word.'⁹ This reflection could be construed as a heuristic, fledgling version of the diathesis-stress model, in which environmental factors interact with innate constitution to induce psychosis in a vulnerable person. Bleuler even contemplated (though ultimately discarded) the position espoused by his more radical associate Carl Jung: that the impact of intense trauma was *sufficient on its own* to induce the catastrophic corrosion of faculties observed in schizophrenia.¹⁰

Bleuler's emphasis on the 'splitting' of psychological faculties actually supplies an extremely powerful fusion of psychotic and dissociative concepts; in some ways the finale of 19th century interest in blending psychosis and dissociation reached its pinnacle with his work.¹¹

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Ironically, however, he was also the partial architect of its dissolution. Although a keen admirer of both Jung and Freud (and one of the first respected, academic psychiatrists to take the new theories of psychoanalysis seriously) Bleuler's insistence on the biogenetic origins of schizophrenia dramatically hastened a loss of interest in trauma-based dissociation and encouraged the medicalisation of psychosis. And so we witnessed the rise of 'illness-model' psychiatry which seeks to yield the secrets of schizophrenia to science; as it does so it endorses the belief that patients are not individuals with meaningful life stories but may legitimately be defined solely on the basis of aberrant biology or brain chemicals.

Today, according to the American Psychiatric Association, dissociation is a psychological defence to trauma (i.e., it allows the mind to distance itself from experiences too extreme for the psyche to process) that is expressed as disruptions to the normal integration of psychological functioning.¹² In contrast, psychosis is understood as a loss of contact with reality, including false ideas about what is taking place (delusions) and seeing or hearing things that are not there (hallucinations).

However, examining the historical forces that shaped their evolution shows us that contemporary interpretations of schizophrenia, dissociation, and traumatic experience are much different from the diffuse and open-minded enquiries which characterised the work of the early theorists. Today, schizophrenia remains the most popular paradigm for psychosis. It exists as a conundrum that has challenged and charged the spheres of the clinical, the psychological, the philosophical, the cultural and the empirical. For me, however, it challenges the profoundly personal. I wonder how a meaningful and legitimate emotional crisis could be so distorted and deformed into inveterate helplessness and demoralisation, into a debilitating disease with a debilitating reputation.

Shattered

Eleven years ago, when I was eighteen, I went mad. 'Gone mad' is what people sometimes say – as if madness is a direction or a place, a discrete destination. But that is not what madness is, for when you go mad you don't actually go anywhere, you remain exactly where you are. And a different person arrives, instead. The doctors called it 'schizophrenia'. I referred to it by other names, which better expressed my misery and confusion.

I struggled artfully with my madness and revelled in the whole frenzied repertoire: the voices, the visions, the bizarre and intractable delusions, and that cruel, infinitely prolonged living death of anguish and isolation that torments you beyond endurance and bleeds you – through exhaustion, hopelessness and loss of self-respect – into a shadow of your former self. It felt as if I was stumbling,

blindly snatching handholds and seeking salvage, but then suddenly all hope would be lost and I would pitch down helplessly, loudly and clumsily without grace or restraint, gathering speed and shock and grazes. You become too tired to stay awake (that gasping, grinding fatigue), yet too restless to sleep (because what dreams might come to you?) You are irritable, miserable, hopeless and lifeless, and no amount of comfort is ever enough. I had a silent, suspended misery about me. At other times I felt black and sluggish and lethal. Even when I smiled I still looked sad. Nothing was a word I associated with myself. I could feel the weight of my own emptiness, lost in the blackness, lost in my own body, and I began to fantasise about finding my missing half, a twin who would heal and complete me and make me whole. I felt utterly alone. My thoughts veered frantically between jarring screams and despairing whimpers. Occasionally, I felt as if I had forgotten how to think. At other times I felt frenzied and terrified, gazing at the world through smoked-glass in which everything was shadowed and grotesque and charged with violent colour. My despair was a patch of syrupy, fleshy blackness pulsing inside me like a living thing. A dark fragment like a bruise, a compelling curiosity, yet distorted and horrible.

The doctors were polite but sceptical, disinterested and intent (it seemed) to sacrifice me on an eerie altar of science. This left me fearful and wordless, burning in obliterating and outraged silence. After that, I resolved to tell them nothing more. My story would be secret and without sound. I would keep my sorrow to myself, loyal even in betrayal. How to sort through the skeins of my ravelling mind?

'*She doesn't seem to want to live in the real world,*' said the nurses. But what kind of criticism was that, when reality was so painful and inadequate, so fragmented and pointless and endless? I vowed I would shift within the awareness of myself, in this world just beyond reality. And I would go on, I would persevere, be silent, suspended and obscure. I would wrap myself in discretion like a fog. I would fight my psychic civil war alone. There was always a part of me that knew these experiences were meaningful: decipherable fragments that could be shuffled together to reveal a lifetime of abuse, denial, blame and betrayal. Memories of being pillaged then discarded, bruised and dripping, '*Please don't hurt me, please, please.*' No wonder I was mad. How I should have loved to look my psychiatrist in the eye (she who told me I would have been better off with cancer, on the grounds that it would be 'easier to cure') and demand that she justify what was so special about her, that she seemed to think she could have suffered the way I had and not been damaged by it.

A Psychic Civil War

Psychological trauma shames, isolates and dehumanises

its victims. It violates one's sense of selfhood, fractures the connections between individual and community, and destroys faith and belief in ordinary systems that provide us with a sense of connection, control and meaning. As Judith Herman observed, it is a *shattering of basic trust*.¹³ In contrast, solidarity, unity and connection creates a sense of safety, validation and humanity – conditions in which to heal, to be heard, to integrate the pain of the past and to move towards the future.

Conversely, however, we currently inhabit systems that actively encourage fragmentation and alienation: systems that ask 'What's *wrong* with you?' rather than 'What *happened* to you?' Painfully and ironically, the place supposed to offer us some refuge – the psychiatric system – is often the thing that nearly destroys us once and for all. This is because it formulates the pain of our lives, and our subsequent reactions to it, in terms of *illness, disability* and carnivorous *mental diseases* like 'schizophrenia'.

In my own case, I was made a passive victim of pathology and statutory services – labelled, medicated and left, derided and despaired of: a hapless, hopeless victim of a preordained genetic tragedy. Three years into my psychiatric career, my 'paranoid schizophrenia' was being managed by a daily arsenal of six different drugs; it had been a catalyst for discrimination, verbal abuse and physical and sexual assault. My family mourned for me as if I had actually died. This daughter and sister who had seemed so promising, so loving, so close to her family, had gradually drifted away to become something else, and it seemed as if there was nothing anybody could do to bring her back. I was only twenty-one years old, yet in effective I had ceased living.

Recently, powerful and persuasive evidence has emerged to demonstrate unequivocal links between schizophrenia and experiences of adversity, oppression and maltreatment (particularly, though not exclusively, childhood abuse). Karon's study of battlefield traumas ('shell-shock') reveals a set of 'symptoms' that today would be classified as schizophrenia. According to him, however, the condition would be better conceptualised as 'chronic terror syndrome'.¹⁴ As a stigmatising label, 'schizophrenia' has a deplorable tendency to conceal rather than illuminate the true causes of distress: just as hearing voices, having unusual beliefs and other signs of psychological anguish draws attention to the existence of an unspeakable, unspoken trauma, the label simultaneously deflects attention away from any possible trauma. People's stories – their social, political and cultural realities – are not explored as coherent narratives but instead are transformed into 'symptoms'. If only hope, trust, comfort and compassion could be dispensed as readily as medication and a stigmatising diagnosis, then perhaps the survivors of powerful traumas would be

less destined to become 'schizophrenics'.

Individuals have to be the authors and arbiters of their own recovery since this is based upon optimism, empowerment and reconnection. The themes of my own recovery reflect the importance of support and encouragement so as to work out ways of helping myself, of understanding what was happening to me, and of taking control of my situation. Most importantly, I had to have hope – the belief that I had a right to recover, to confront this strange, subconscious world in a constructive way and to find practical healing through the confidence to look those experiences in the eye and make sense of what was happening.

Recovery is also about acceptance and ownership. I had always been told that the voices I heard were a clear indication of being insane, and their presence became increasingly frightening and demoralising. In effect, I felt as if I was engaged in a kind of psychic civil war in which I was encouraged to take an aggressive stance against my own 'diseased' mind. It was only several years later that I began to appreciate that the voices were by no means an abstract and arbitrary indication of a mental illness, but instead a significant, interpretable experience whose meaning and purpose might be deciphered.

Ultimately, I would come to realise that the voices were parts of myself (albeit dissociated parts), internalised depictions of my world and born from my experience. And that, in order to cope, my conscious mind had dissociated from the trauma and created those detached and disowned 'selves', so as to escape in my mind from the pain. Resolution meant ceasing to resist the voices and instead trying to understand what they wanted, why they were there. It meant acknowledging them and the context in which they emerged. It was crucial to replace the fear, violation and aggression that had previously existed between my internal voices with a growing sense of communion, collaboration, safety and respect. This was because the voice of each self was a part of my whole self: our life was a shared project in which we proceeded together. However terrifying they sometimes seemed, the voices held important truths about my reality, my life and experiences, and as such they warranted respect, consideration and compassion.

It is difficult to respond in a caring and empathic way to threatening and malicious voices. Renouncing them (as well as the emotions they represent) seems an infinitely preferable option. But when I realised that those voices belonged to the hurt child part of myself – the part that protected me when I was young – it became easier to respond to them with kindness, reassurance and support. And in turn, as the voices learned to trust me, even the most menacingly hostile voices began to relent and revealed themselves as the identities of a vulnerable,

frightened and abused child who hid behind an initially terrifying facade. Akin to the original concept of the 'split mind' (i.e., as a protective division of the experience of the self), the memories, thoughts and emotions of my dissociated selves were not directly available to conscious introspection and control. Breaking down those barriers helped me to become whole again.

Unity, Recovery and Discovery: Healing the Fractured Self

It seems to me that pessimistic and paternalistic mental health services that focus on stigmatising, reductionist diagnoses such as 'schizophrenia' are no longer defensible. In my case, the social, emotional and psychological damage inflicted on me by the system was catastrophic. Thankfully it wasn't irreversible. But equally, I can look back on those years and appreciate that, to a frightening extent, my survival was *simply a matter of luck*. This is horrifying and I very strongly believe that the next generation of terrorised and demoralised teenagers needs more than luck to protect them. Being stifled with neuroleptics has nothing to do with recovery. Recovery is about confidence, choice and collaboration; not pity, but empathy; not coercion and compliance, but compassion and having one's dignity and diversity acknowledged and supported. And it's about restoring the capacity to feel joy, to move beyond surviving the past and creating a rewarding future.

I believe that the evidence is now very clear, and that it is neither scientifically or morally acceptable to conceptualise distress as the symptom of disease. Rather, such distress denotes authentic and significant events (albeit events that are painful, fearful and overwhelming) which communicate in a *metaphorical* way about the person's life. I would characterise the hallmark 'symptoms of schizophrenia' as messengers that communicate compelling information about genuine problems in a person's world. Hence, it simply makes no sense to 'shoot the messenger' and deny the content of the message. True to the spirit of much of the very earliest work on the problem, the new paradigm should be one of open-minded exploration, discovery and humanity. The normal psychiatric response or cure is to drug the person so as to sedate and silence him or her. The recovery response is to try to understand, accept and integrate the splintered emotional meanings of the person's experience.

The Chairperson of the UK Hearing Voices Network, Jacqui Dillon, has written:

We do not seek to reduce people to a set of symptoms that we wish to suppress and control with medication. We show respect for the reality of the trauma they have endured, and bear witness to the suffering they have experienced. We honour people's resilience and capacity to survive often against the odds. The reduction of

people's 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. Their routes to recovery are hindered. Rather than pathologizing individuals, we have a collective responsibility to people who have experienced abuse to acknowledge the reality and impact of those experiences and support them to get the help they need. Abuse thrives in secrecy. We must expose the truth and not perpetuate injustice further. Otherwise today's child-abuse victims will become tomorrow's psychiatric patients.¹⁵

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A HISTORY OF TREATMENTS FOR SCHIZOPHRENIA & DEPRESSION

Peter Bullimore

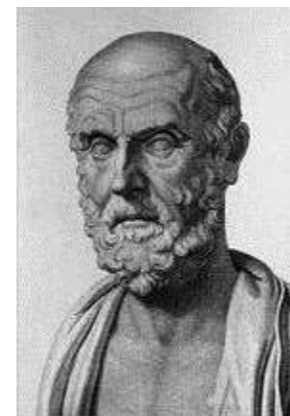
In the beginning

It is thought that in early human history (before large settlements or cities), mental illnesses were believed to be the result of possession by spirits or other forms of supernatural entities. Treatments for mental illnesses during this time are hence thought to have involved a variety of methods which attempted to remove such spirits. One commonly cited example is trepanning. Human skulls dating back to around 10,000BC have been found with holes in them (right). It is commonly believed that this reflects an early medical intervention aimed at releasing the evil spirits from a person.



In early civilisations such as Babylon and Assyria (around 2000–1000BC), a distinction was made between medical illnesses which were seen to have natural causes (such as dysentery, worm infections, lung and eye diseases) and mental illnesses which were thought to have supernatural causes (such as hallucinations and delusions). Mental illnesses were often thought to have been caused by being touched by the hand of a god. The two types of illnesses were treated by different people. Medical illnesses with natural causes were treated by an *asutu* who used a range of herbal cures or surgical techniques. Mental illnesses were treated by an *ashipu*, or medical exorcist, who may be regarded, at least in part, as history's first psychiatrist.

By the time of Ancient Greece (around 500BC) the view of mental disorder shifted to a medical view. Medical practitioners treated both physical and mental illnesses, and within the same explanatory framework. A key figure in ancient Greece was the physician Hippocrates (c. 460–377 BC.) Hippocrates moved firmly away from the idea that mental disorders were caused by spirits or supernatural entities.



Hippocrates

Instead he explained them by using the Greek theory of humors. This proposed that the body was made up of four basic substances (black bile, yellow bile, phlegm, and blood). And that illnesses in general, including mental illnesses, resulted from an imbalance in these humors. Mental illnesses would be treated by the physician creating a plan for the patient's diet,

surroundings, exercise, and sleep. If this didn't work, more potent herbal drugs were used.

For example, black bile was associated with earth, and being cold and dry, and melancholia (depression) was thought to be due to an excess of that 'humour'. As such, a regime of food and exercise was devised to restore the balance, with the use of herbs or foods associated with hotness and wetness. Mania was thought to be due to too much yellow bile. Since yellow bile was associated with fire, and was hot and dry, mania would be treated by the use of herbs and foods that were cold and moist, as well as by activities such as cold baths.

Actually, this slightly oversimplifies matters. In fact, treatments took place in a number of stages. Firstly, the acute attack itself would be treated. Then post-episode treatment would occur in two steps. There would be a restorative part designed to build up the patient's strength, and a further part to change the patient's constitution to prevent reoccurrence. For example, if the patient experienced an episode of mania, during the attack itself the physician would prescribe rest, gentle massage and a limited diet. After the attack, the physician would suggest more rest, dietary changes, massage, and music therapy. And then, so as to change the person's constitution, the doctor would advise violent purging (by giving the patient drugs such as hellebore, which caused vomiting and sickness), sun-bathing, hot and cold baths, and finally travel, particularly sea voyages.

What seems to have been the case in Ancient Greece is that the physician for a mental disorder was permitted to be a kind of trickster. For example, a man with the delusion that he had no head was made to wear heavy head-gear. Similarly, a woman who believed she had swallowed a snake was given an enema, and the physician quickly placed a small snake in her faeces. It is also interesting to note that the Greeks used music in the treatment of mental disease, suiting the type of music to the nature of the case, for example, by employing pleasant music for those suffering from depression.

During the European Middle Ages, the belief that mental illnesses could have supernatural causes resurfaced, although mental disorders were understood potentially to have natural causes. As with the Greeks, the natural causes that were understood to cause madness included poor diet, alcohol, overwork, and severe grief. However, Christian authorities also believed in supernatural causes, including sin or demonic influence. Yet, as Kroll and Bachrach¹ have argued, sin was only rarely employed as an explanation, and then mainly because the person was an enemy. During this period, treatments were varied, ranging from purges, bloodletting and whipping, to fasting, prayer and exorcism.

The birth of psychiatry

From the 19th century onwards, medical psychiatry became the main paradigm for understanding and treating mental disorders. Psychiatry was firmly committed to locating the cause in the body or brain. In the early 1900s, for example, at the New Jersey State Hospital, Dr Henry Cotton tried to test the theory that mental illness resulted from toxins, released by a bodily disease, which ended up in the brain. His test was truly horrific. First he removed the patient's teeth. If that failed, he went on to remove the tonsils, the testicles or ovaries, the gall bladder, or other parts of the patient's body. Forty-five per cent of such patients died. In the first half of the 20th century a series of other radically invasive therapies were devised for mental illness. These include, prefrontal leucotomy, insulin coma and ECT.

1) Prefrontal leucotomy and lobotomy

Prefrontal leucotomy is a brain operation in which the nerve fibres leading from the front of the brain to the back are cut. This was devised by Egas Moniz, a Portuguese neurosurgeon.

The idea was then taken up by Walter Freeman who performed a similar, though less precise, procedure termed a lobotomy. He would stun patients by electroshock before inserting an ice pick through the bone near the eyeball and moving it roughly from side to side. Freeman travelled round the USA in a van he nicknamed the 'lobotomobile'. His most famous patient was J F Kennedy's sister, Rosemary. She was left incontinent, able to utter only a few words, and in an institution for the rest of her life.

Moniz received the Nobel Prize for Medicine. Actually, this was not for developing leucotomy but for being the first person to x-ray the brain. Moniz was shot by one of his patients in 1939, but he survived.



Egas Moniz on banknote

2) Insulin coma

This technique was devised for use with schizophrenia. Patients are put into a coma by means of the drug insulin. This starves the brain of sugar. In early studies it was claimed that 88% of patients responded well. However, not only did some patients die due to the technique but the positive evidence was eventually shown to be flimsy. An American survivor of 50 forced insulin coma treatments, Leonard Roy Frank, described it as "the most devastating, painful and humiliating experience of my life".²

Why did such a brutal therapy become popular? Frank thinks it was because "... it meant that psychiatrists had something to do. It made them feel like real doctors instead of just institutional attendants."

Why were psychiatrists allowed to get away with such barbaric treatments? Bentall argues that the many harmful treatments which can be seen in the history of psychiatry have resulted from patient's objections being ignored, as a *matter of supposedly scientific-medical principle*, because the fact of having a mental illness (being irrational)

disqualifies them from offering a reasonable opinion about their experiences.

Hence the need for a strong service-user movement is absolutely vital.

3) Electroconvulsive therapy (ECT)

Electroconvulsive therapy was first 'discovered' as a method of treatment for depression in the 1930s. The process was invented after psychiatrists observed electric shocks being used to stun animals prior to slaughter in the local abattoir. There is evidence that ECT is effective in relieving depression in the short-term, i.e., over a period of a couple of weeks. However, as Bentall notes, when patients are followed up over longer periods of time, the relapse rate can be over 80%. Bentall concludes that its use as a psychiatric technique remains questionable (p. 213). Given that the side effects of ECT include memory loss, confusion, headache, nausea and emotional shallowness, that it has a high relapse rate, that no one knows how it actually works, and that its benefits are short term, this seems a fair conclusion. Also, a worrying audit in 1998 reported that only one-third of the UK's ECT clinics met the standards of the Royal College of Psychiatrists.

It should also be noted that, due to campaigning pressure groups, the use of this technique has been severely limited in Holland and Italy. The use of ECT does appear to be generally in decline. For example, a survey found an overall decline in the number of ECT applications and the number of patients treated in the United Kingdom between 1999 and 2006. Nevertheless, about 20% of all psychiatric patients still receive electroshock, and there has been a worrying increase in the proportion of patients treated whilst detained under the Mental Health Act. Thankfully, insulin coma treatment is no longer used and leucotomy only very rarely (although leucotomy by electrical probe has a few fanatical 'neuroscientific' supporters).

So the two main treatments of mental disorder today are drugs and the talking cures.

Pharmacological drug therapies

a) Pharmacological drug use in depression: the drugs don't work

Drugs, for example Selective Serotonin Reuptake Inhibitors such as Prozac, have been found to be effective in around 65% of cases of depression. However, relapse is a common problem when the medications are stopped. And so it has been argued that it is more effective to combine drugs with CBT.

That sort of information is typical of what is stated in contemporary textbooks. However, this picture is not entirely accurate. More recent meta-analyses, which consider results from a large number of studies, have found that there is *no* overall clinical effect of the antidepressants.

This is not to say that patients do not show improvements in their symptoms when they take antidepressants, because they can. But the majority of this improvement appears to be due to the placebo effect: patients that take placebos also see their symptoms improve by a similar amount.⁴

b) Pharmacological drug use in schizophrenia: the drugs might work, but ...

Around 30% of patients with schizophrenia will experience no relief at all from their symptoms through taking antipsychotic medications. For the other 70%, there is evidence that antipsychotic drugs can help with experiences such as hallucinations and delusions, in the short-term. However, the drugs appear to work not by making such experiences go away, but rather by making patients less bothered by their symptoms. Furthermore, the therapeutic effects of the new generation of antipsychotics – such as Olanzapine – have been found to be only 'moderate'.

In the long term, things are not so clear. Bola looked at patients who had their first episode of psychosis and who were followed up a year later. Patients who were given medication did no better than those who were not given medication. This needs to be considered in the context of the extensive side effects of such antipsychotic treatment such as:

- Lactation in women, and swelling of the breasts in men
- Skin rashes and sensitivity to sunlight
- Weight gain (particularly with Olanzapine), and associated blood pressure and heart problems, and diabetes
- Agitation and restlessness

Bentall concludes that 'first-episode patients may do well with only a brief period of antipsychotic treatment, or without any drug therapy at all' (p. 234).

There is also other evidence arguing against the effectiveness of antipsychotic drugs. Richard Warner's historical survey concluded that the introduction of antipsychotic drugs had not improved the outcomes for patients with schizophrenia. Although, interestingly, he noted that economic factors might be important: patients recovered less well during recessions than during booms.⁶ Furthermore, a study of patients with schizophrenia by the World Health Organisation (WHO) found that patients in developing nations (e.g., India and Nigeria) had better outcomes than patients in the industrialised nations (e.g., USA and UK). This was so surprising that WHO ran another study in which they found the same results. Although there are arguments about the meaning of these studies, they clearly show that those countries with the highest availability of antipsychotic drugs (the industrialised countries) had worse outcomes than those where the drugs were less available.

Psychotherapy: The talking cure

Training in social skills, Cognitive-Behavioural Therapy (CBT) and mindfulness-based Cognitive Therapy all seem to

provide some benefit for a range of mental illnesses. CBT is the most studied of these talking cures. There is evidence that it is effective both for psychosis and for bipolar disorder, but only moderately so.⁷ However, Buddhist meditation techniques have also been found to be useful for patients who have not responded to more traditional forms of psychotherapy.

One of the best examples of this is the Soteria House study by Loren Mosher. (Soteria is from the Greek, meaning 'Salvation'.) A two-storey house in a poor area of California was staffed by people with no formal training in psychology or psychiatry. The staff worked long shifts, effectively living with the psychiatric residents. In posh terms the treatment was called 'interpersonal phenomenology'. In reality, this simply meant that the staff tried to put themselves in the patients' shoes. Except in a handful of cases, no drugs were employed. The study met all the proper scientific criteria. A two-year follow-up found that 43% of the patients still hadn't used psychiatric drugs, and that those patients were doing just as well as – or perhaps slightly better than – a similar sample of patients who had undergone conventional psychiatric treatment. Other studies have found that antipsychotic medications have no measurable positive effects when patients live in a supportive home environment.

Other non-medical interventions

Patients with schizophrenia returning from hospitals to live with critical, hostile, or emotionally controlling parents are more likely to relapse. A systematic review of 25 individual studies found that patients whose relatives were educated about psychosis and who were helped to develop skills to resolve family conflicts had 20% fewer relapses. This is interesting because neuroleptic medication also seems to result in around 20% fewer relapses, too.

There is preliminary evidence that body psychotherapy, which involves various physical exercises and music therapy are both effective for treating schizophrenia. The modern use of music therapy reprises the use of music in Ancient Greece.

Important practical aspects of daily life have also been shown to aid recovery. Many patients with schizophrenia feel that being unable to get a job again impairs their recovery. The science supports this: patients who are able to get jobs see their symptoms improve.

And so contemporary research appears to suggest that treatments for mental illness need to take a holistic approach. There may be a limited role for drugs, and talking cures also seem to offer some benefit. But the very practical aspects of life also need to be addressed in order for recovery to take place – for example, people need employment, hope, purpose in life, friends, social support and safe housing. No one treatment is sufficient.

Conclusions

Treatments seem to go in cycles. In 10,000bc holes were drilled into the skull, probably to try and cure mental

illness. In the 20th century, psychiatry resorted to similar techniques with horrific results. If we look back to Ancient Greece we see how a range of techniques were employed, including kindness, music, diet, exercise and herbal drugs. This is uncannily similar to the treatments we have today. Whilst drug treatments seem to be ineffective for some conditions (e.g., depression) there is evidence that they can be useful in the short term for some people diagnosed with schizophrenia. Yet what emerges from the contemporary literature on talking cures is that simple kindness and support for people diagnosed with a mental illness is just as effective. It is surprising that this should come as a surprise.

Finally, it seems clear that decisions about psychiatric policy should heed the growing literature which shows a very high prevalence of earlier (childhood) trauma in those diagnosed with 'mental illness'. Read suggests that in the future, treatments may want to address such experiences so as to help those who have experienced them to deal with the psychological and practical problems that they face.

Book Review: The Meanings of Madness Eleanor Longden

Agnes's Jacket: A Psychologist's Search for the Meanings of Madness

Gail Hornstein. New York: Rodale Books, 2009. £29.95

Unusually for such a prestigious academic, Gail Hornstein, Professor of Psychology at Mount Holyoke College, Massachusetts, is less concerned with the theories, models and philosophies of madness than by the testimonies and experiences of those designated 'mentally ill'. Her new book, *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness* follows this tradition by taking as its opening premise the intricately stitched jacket of a seamstress incarcerated within the Hubertusberg Asylum in 19th century Germany. The words that Agnes Richter embroidered into her institutional garment form a mysterious autobiographical text, 'a needle and thread narrative', which defies translation by contemporary scholars and historians. As Hornstein writes: "For me, Agnes Richter's jacket precisely captures the fundamental conundrum of madness, an experience rich with symbolic meanings that are indecipherable by ordinary means."

Throughout the book, Hornstein invites the reader to share her extraordinary journey as she attempts to unravel the meanings of mental distress: its penalties, its rewards, and the various ways in which people have tried to understand this most absorbing of human mysteries. The pages are filled with a host of colourful and compelling characters, from renegades, revolutionaries and activists, to pioneering psychologists, psychiatrists and members of the Hearing Voices Network self-help groups. An ongoing theme is the

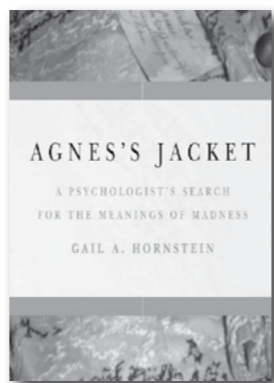
And we should not forget the words of Carl Rogers: The relationship with the person is more important than the therapy.⁸

Full references for this article can be obtained from the author: peterbullimore@yahoo.co.uk

1. Information in this section is from R. P. Bentall: *Doctoring The Mind*, Allen Lane/Penguin, 2009.
2. L. R. Frank (ed.): *The History of Shock Treatment*, L. R. Frank, San Francisco, 1978.
3. I. Kirsch et al: 'Initial severity and antidepressant benefits: a meta-analysis of data submitted to the Food and Drug Administration.' (2008) *PLoS Med.* 5 (2), e45.
4. I. Kirsch and G. Sapirstein: 'Listening to prozac but hearing placebo: a meta-analysis of antidepressant medication.' *Prevention & Treatment*, (1998), 1, Article 0002a.
5. See Bentall, 2009.
6. R. Warner: *Recovery from Schizophrenia: Psychiatry and Political Economy*, Routledge, 1985.
7. R. Bentall, 2009.
8. H. Kirschenbaum: *The Life and Work of Carl Rogers*, PCCS Books, 2007.

vibrancy and resilience of psychiatric dissidents and survivors. Just as Agnes fought for the right to tell her story through her painstaking stitches, Hornstein shows how generations of subsequent patients have resisted attempts at silencing and suppression.

From trauma and recovery, spirituality, and outsider art to the pernicious, profiteering influence of the pharmacological industry, *Agnes's Jacket* provides an enthralling, imaginative and, at times, shocking exploration into psychiatric systems past and present. Impeccably researched over the course of several years, the result is a profound, original and extremely important piece of work. Hornstein's humility, grace and radiant intelligence are laced through every page, as is the wit, wisdom and insight of the numerous people who share their personal stories with her. As Patrick McGrath recommends it, *Agnes's Jacket* "is a true literature of protest". This book is too full of wisdom, hope and humanity to keep to yourself. Buy it, read it, absorb it, then give it someone you really love.



write to *asylum* ...

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Spaceships Philip Thomas

I smell his body as I follow him through the door into my office. His sweat mingled with that of the previous owner of the old jacket he had found, pockets empty, folded over a seat in a bus station.

He comes in, sits down and without invitation starts by telling me that he has been abducted in a spaceship and taken to the sun. He is empty-eyed, his skin matchbox rough, his speech xylophone thin. I unbutton my jacket. The superfine wool squeaks against my carefully pared fingernail. Then I thumb through a blank sheaf of papers that stare expectantly up at me.

'It drew me in. I was tired and curious.'

'What did?' I ask.

'The ship. It blotted out the sky and stood there, its silver hull something from another age.'

'Can I draw you a spaceship, Dad? I bet mine's bigger than yours.'

'Not now, son. You have a maths exam tomorrow.'

'Oh, Da-ad.'

'Tomorrow, when I get home. If your mother says you've done your revision.'

I doodle a spaceship in the margin – a kid's spaceship standing on its tail-fins, pointed nose reaching for the stars. A rich kid's spaceship. Blue-eyed Dan Dare is on board, his flying jacket draped casually over his manly shoulders as he grips the stem of his pipe in steely-jawed silence. And Digby, curious cherubic Digby, the cheerful Northern chappie who knows better than to question his superiors.

'There were strange noises too,' he says interrupting my reverie. 'Eldritch noises, sighs from an otherworldly being.'

'Hell ditch?' Strange phrase that, I think. He's made it up.

'Can I just check that I've got that? H-e-l-l-d-i-t-c-h?'

'No, Eldritch. E-l-d-r-i-t-c-h.' Then he leans forward and looks me squarely in the eye for the first time. He whispers with a measure of urgency. 'You are listening to me, aren't you, doctor?'

'Sure,' I reply.

'Look Dad! My spaceship's exploded.'

'I thought I'd told you to go and do your revision.'

'Please continue,' I say, as my spaceship leaves the margin and takes off for the planet Cryptos.

'The hatch slid silently open. The September mist agitated and dispersed, as a hum and a golden glow came from within. She called me. I tried to turn away,' he says, 'but she held me in her grasp. Held me in her grasp!' he repeats and fades into silence, his jaw slack, eyes unfocused, his right arm extended as his fingers grab fresh air. It is as if by placing his hand and fingers in exactly the right position, he will be able to recreate the precise moment that he

struggles to recreate in words. He is frozen in remembrance of the absent unforgettable. I glance at the clock on the wall behind his head. I have to be at the station by six-thirty.

'So, what then?' I prompt.

'It drew me in. I didn't want to, but it made me. She made me.'

'Who?'

'The Sun god.'

I scribble some more.

'Dad, you won't believe this. Dan Dare's been captured by the Crypts. He and Digby are being held prisoner by Commander Zorg.'

'I'm not going to tell you again, William. Will you go and start your revision.'

'Did she say anything?'

'Yes.' His arm relaxes. He raises his eyes to the heavens. 'She spoke music, a shimmering shower of liquid arpeggios. And she set the controls for the heart of the sun.' I scribble furiously. 'She took command of the levers and switches, and the ship took off. Jade and amber dials flashed, crystals quivered as the ship came to life and headed for the heavens.'

I ease myself back in my seat for a moment, and he asks for a glass of water. I point to the carafe on the table. He pours himself some, clumsily, splashing it over the magazines, and drinks like a sun-stroked man. He tosses off great draughts with a mechanical clunking sound from somewhere deep inside his body. He pours himself another and downs it in similar fashion. Then he slams the glass down on the table, and wipes his lips with the back of his hand. He gets up and wanders over to the window. He stares out hard into the late summer sunshine, but his eyes are not screwed up against the photon flux. His crows' feet stand out white against his brown skin. Perhaps he's a Desert Rat. He smells like one.

'Have you heard anything else strange?'

'The engines,' he replies, and he describes how the humming changed. 'It reminded me of a piece of music, like the beginning of Ligeti's *Melodien*. Have you ever heard it?'

I frown. He's definitely making this up. I'm convinced he is. This is a well-oiled story. It comes out too easily, like shit off a shovel. Shit off a shovel! That's a good one, I think to myself. I must remember that. 'Er, no. I don't think so,' I reply

'Just a beautiful sound as the earth disappeared beneath us and the ship headed for the sun.' He says he was afraid, terrified. Sweat beads his brow. He slurps more water. 'I shouted no! We'll all be killed. Remember Icarus! But she laughed, a timeless chime of cascading quavers and triplets. She turned to face me but she was terrible. I could not behold her face. She said it consumes only because we need to believe it does.'

I pause a moment and ask him to repeat what he has just said. He does. It consumes only because we need to believe it does. I write that down. 'But that doesn't make sense,' I reply. 'The sun's driven by nuclear fusion. Its surface temperature is 6,000 degrees centigrade. You would be vaporised instantly.'

But he continues. 'We passed through the outer layers. I

was blinded for a moment, but I could hear everything and see again when we finally touched down on its surface.'

'Let me be quite certain that I understand what you're telling me. You landed on the sun, right?' I take my neatly pressed handkerchief out of my pocket and cough into it in a considered manner.

'Yes,' he says. 'It was indescribably beautiful.'

'You must see this, Dad. Look, there's the Mekon floating on his personal flying saucer. Then he aims his gammatron gun and fires. But look! The death ray is deflected by the badge on Dan's helmet and bounces back destroying the Mekon in a puff of green smoke.'

'William. How many times do I have to tell you? Stop this madness and go and do your revision.'

'And what was it like on the sun?'

His eyes glitter. 'It was a beautiful garden, a strange profusion of flowers, shrubs and trees, snowdrops and meadowsweet in full bloom, all at the same time. A small brook gurgled through reed beds. The crowns of great trees swayed and yielded to a soft breeze, vast oaks, beeches and limes in full leaf, dappling the ground with their restless rustling. But at the same time the earth was covered by their decaying leaves. And there was birdsong, the voices of the gods laughing, playing and loving. A thousand scents filled the air of the garden of love.'

I listen intently, palms together, the tips of my middle

fingers touching my lips. Then I shiver. Something deep within me is touched for an instant but then vanishes without trace: poetry that once comforted me as a child, long forgotten lines that echo from my mother's lips, the whisper of a fiction that held me enthralled one stormy winter's night. My mouth is dry, my eyes burn.

'I looked up but there was no sky,' he continues. 'No infinite blue horizon, no white clouds, no sun, just a nameless dome with countless coruscating needles, casting an ambiguous light whose shadows disclosed another reality. In this world all possibilities appeared simultaneously, transforming instantly and endlessly. The brook flowed through the reeds forwards and backwards in time. I heard the silence of the birds in their song. I knew all beginnings and endings but knew nothing, like the newborn child that chokes its mother's fluid from its lungs as it gasps for life.'

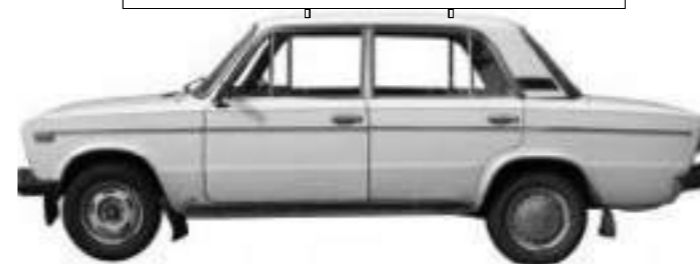
I put down my pen down and blow my nose, and take a deep breath. 'Time's up,' I say. 'Increase the quetiapine to four hundred milligrams a day, and see you in three month's time.'

'But I've been abducted by a spaceship from the sun!' he protests, as I usher him out of my office. He leaves. I sit alone.

'Well done, son. Your mother and I knew you'd do it. Now then, what are you going to be when you've grown up?'

'A psychiatrist.'

auto-schizophrenic
vehicle DANGER!



'I've sorted it,' he announced, as he rooted in his nostril with a Big Pharma Auto Solutions souvenir pen (from an all-expenses-paid conference in Honolulu). 'All your cars are auto-schizophrenic.'

I was somewhat taken aback.

'What are you talking about?' I said. 'The Volkswagen has no engine, the Capri has a faulty rear-window demister and the Ford has only got three wheels. How can you say they are all auto-schizophrenic?'

'Don't take that attitude with me sunshine or I'll impound the lot of them,' he replied, menacingly.

'You can't section a bloody car!' I said with a rising voice.

'Oh yes I can. All six of them,' he said.

We had reached an impasse.

I tried to establish a reasonable relationship. 'How have you come to the conclusion, in about two minutes, that all my cars can be diagnosed with auto-schizophrenia?'

'I'm glad you asked,' he replied. 'It's all based on a 100-year-old classification system based on a prototype Audi two-seater. Well, one-seater really, the other seat was for the man who walked in front of the car and waved a flag to avoid frightening horses.'

I tried to seek clarification.

'Are you telling me that you have diagnosed all my car collection with auto-schizophrenia on the basis of a system when the most common form of transport was a donkey?'

'Absolutely, squire. If it's not broken don't change it. That's our motto at BPAS. Obviously, there have been some refinements over the years, and thanks to the involvement of some influential National Socialists we now have definite first-rank symptoms of auto-schizophrenia, which are a proven sign of the diagnosis. For example, a faulty radio, especially a failure to pick up Radio 2, is a definite sign. It's a fact.'

I digested this information. The magpie stopped singing and looked at me quizzically.

'How can we solve this?' I asked.

'Easy,' He replied. 'We'll just slip some anti-psychotic auto-medication into the petrol tanks. Your cars will be fine – job done!'

'Will that work?' I asked, suddenly excited.

'Certainly governor,' said the mechanic. 'It's proven time and time again. Research, you see.'

'Who did this research?' I asked. I thought it was a fair question.

'The makers of the anti-psychotic auto-medication,' he replied.

Even he looked sheepish. The magpie sobbed.

'Are there any side effects from putting this stuff in my cars?' I asked.

He looked me up and down.

'You're a bit of a thinker, aren't you? The answer is,

frankly – yes.'

'What are they,' I said.

He coughed to cover his discomfort.

'Well, your car might die, it will never run properly again, and the weight-gain can be astonishing.'

'How does a fucking car gain weight?' I demanded.

'I know,' he acknowledged. 'Someone brought in a Fiat two years ago and now we can only move it with a crane. Still, it's better than auto-schizophrenia. Science has to progress.'

'Is there anything else I should know?' I asked.

'Well, yes, one thing,' he replied. 'The general public are nervous about auto-schizophrenic cars because of some bad press. As responsible mechanics we need to recognise this so, as we speak, the lads in the paint-shop are spraying all your cars black and attaching luminous hazard signs to the roof racks.'

'mightn't that affect the way the cars get treated by other drivers?' I asked. By now the magpie was giving us his full attention.

'Probably,' replied the mechanic. 'Best to keep them off the road really. Have you considered scrapping them?'

'No' I said.

I tried to summarise.

'Have I understood this correctly? I've brought you six cars, all different ages, all with different problems that need some care and attention. You have diagnosed them all with auto-schizophrenia. This is based on a hand-written, one-hundred-year-old manual for a prototype Audi from the Victorian era, that no one can agree about. Your solution for the cars is to pump the petrol tank with dangerous chemicals that might not help and may damage them forever. The only evidence that this will work comes from the people who make the chemicals. You want to paint the cars black and attach hazard signs to the roofs, and you have suggested that they all be scrapped, or at least left to rot in a dingy garage. If I disagree with this, you will auto-section them. Have I understood correctly?'

'Spot on,' he said. 'Isn't progress a wonderful thing?'

'I'll take my business elsewhere,' I said. 'I'm going to another garage.'

He smiled.

'No point,' he said. 'mechanics round here all went on the same training course and stick to the same manual. We believe in choice, but the choice is ours!'

The magpie looked astonished.

I walked away, shaking my head in disbelief. In amongst the litter on the forecourt, I noticed a leaflet inviting cars and car owners to a join a support group to try to find another solution.

So I took out my mobile phone and dialled the number.

The magpie clapped its wings.

SCHIZOPHRENIC VEHICLE REPAIRS

Paul Hammersley

In this special edition of Asylum you will read a number of different critiques of the schizophrenia diagnosis. Some analyse the pseudo-science that supports this questionable 'condition', others consider the stigma attached to individuals who receive the diagnosis, and some that take an historical overview.

This is different. It's not an academic piece. It's an attempt to step away from the issue so as to see it for what it is. I hope this article doesn't offend anyone but if it does, I can live with that. Because it's far less offensive than discrimination, life-ruining side effects and hopelessness.

If psychiatrists were car mechanics

my uncle Jack left me a present – his car collection. There were six cars, some vintage, some newer. The American cruiser was old but beautiful and had some tricky hydraulic problems, the 1960s morris minor was in very good condition and was only missing a rear-view mirror. All needed some love and repair. I booked them into a local garage to get them all up and running. The man said that he would have all the cars brought in on a trailer and see what he could do.

I turned up on the arranged day to discuss my newly acquired cars. A mechanic strolled towards me casually scratching his testicles. I noticed that underneath the oil stains of his overalls I could clearly see the logo 'Big Pharma Auto Chemical Solutions', but I ignored it.

'Can you have a look at my cars?' I said.

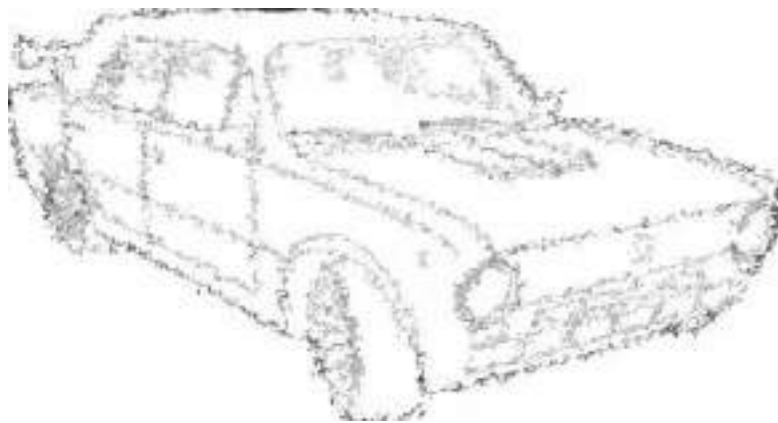
'Certainly sunshine,' he replied. 'You get a cup of coffee and I'll have a look.'

'Do you need the log books to know something about the cars?' I asked helpfully.

'No need,' he said. 'History is irrelevant. All your cars have a chemical imbalance. I'll sort this out. leave it to an expert.'

I was dubious. A magpie clattered in the distance

Before my vending-machine coffee had gone cold the mechanic called me back.



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Asperger's Syndrome and Schizophrenia: *exploring the overlap between the two diagnoses*

There are adults who have a diagnosis of both Asperger's syndrome (a high-functioning form of autism) and schizophrenia, and for whom there is considerable controversy as to the correct diagnosis. Concerns have been expressed by some clinicians, service users and families that the misdiagnosis of Asperger's syndrome as schizophrenia not only results in inappropriate care and treatment, but might actually compound a person's problems (gould 2010a, 2010b; Tierney 2011). When this is viewed from a perspective that doubts the validity of the concept of schizophrenia (e.g. Boyle 2002), or of the concept of diagnosis more generally, an extra dimension is added to an already complex situation.

The idea is gaining ground that diagnosis is less important than getting the right support tailored to the individual. We might be moving towards a time when diagnosis becomes irrelevant, or at least much less significant. However, we are not there yet and most psychiatric assessments still result in people being given a diagnosis that determines the kind of treatment they receive. This article examines an issue that centres on diagnostic categories, and it also considers the implications for moving beyond this approach.

Unlike some other conditions, there is a strongly held view in mainstream psychiatry that a person cannot have a dual diagnosis of Asperger's syndrome and schizophrenia. In theory it has to be one or the other, but in practice (and from the point of view of families and service users) people often have both diagnoses. Even to use the phrase 'dual diagnosis of Asperger's syndrome and schizophrenia' implies a questioning of the conventional view.

I became interested in the different perspectives on the overlap between Asperger's syndrome and schizophrenia because a member of my family has had both these diagnoses, and the process of getting the right care and treatment has been fraught and difficult over many years. I decided to do some research about the overlap between the two diagnoses with an emphasis on the views of service users and their families. I am a social anthropologist working in health services research, and my personal experience of this 'dual-diagnosis' issue allowed me to see an area where research is needed. The three-way interaction between service users, their families and professionals seemed the obvious focus for examining this overlap between the two diagnoses.

'Psychosis' in Asperger's syndrome and schizophrenia

The way of being known as 'psychosis' is the key feature of the overlap between the two diagnoses. Schizophrenia is generally regarded as more or less synonymous with 'psychosis', whereas this is clearly not the case for Asperger's syndrome. However, many Asperger's syndrome specialists and relatives of those with this condition are aware that psychosis-like symptoms can be one aspect of the syndrome. The explanation is that a person with Asperger's syndrome experiences a high level of ambient anxiety due to difficulties with social functioning, and this lowers his threshold for tipping over into chaotic behaviour which is unmanageable for others and is viewed as 'psychosis' (personal communication with Ian Ensum, a clinical psychologist who leads the Bristol Asperger's Syndrome Service). These psychosis-like

symptoms (or chaotic behaviours) can lead to a diagnosis of schizophrenia if the psychiatrist giving the diagnosis is not aware of how Asperger's syndrome can present. When clinicians, relatives or the service user him or herself are of the opinion that this is not the right diagnosis, and if an assessment for Asperger's syndrome is subsequently carried out, the individual can end up with a 'dual diagnosis' due to differing opinions about which diagnosis is correct.

Concepts and models

When individuals have a diagnosis of both Asperger's syndrome and schizophrenia there are several different explanatory models for what is taking place. The various explanations are situated within different conceptual frameworks that attempt to explain or interpret 'psychosis'.

For the term 'psychosis' there are different understandings of cause and effect that shape how a person's presentation is interpreted. The mainstream psychiatric view emphasises hallucinations and delusions as the main features, and this as evidence of schizophrenia (Warner 2004). From an autism perspective, behaviour which is interpreted as 'psychosis' can be seen as the 'acting out' of anxiety, which can be exacerbated by compulsion and coercion (Volkmar et al 2005: 269–70). The psychoanalytic view emphasises the contribution of unresolved problems from early development (gleeson et al 2008; Alanen et al 2009). The view from critical psychiatry links the personal issue of post-traumatic stress disorder (PTSD) with societal inequality and power relations (Double 2006). Psychosocial approaches highlight the radical idea of recovery from 'psychosis' without medication (Garfield and Mackler 2008). Service-user and family perspectives present different versions of a person who has been misunderstood and subjected to standard practice rather than having services tailored to their particular needs (Estroff 1985; Hardcastle et al 2007). This list can be extended to include spiritual and religious interpretations of 'psychosis', and the view that the experience can be a process of creativity (maitland 2008:14,248–9; Tammet 2009:211–16).

These different interpretations or models are evident in, and embedded within, the interactions between service-users, families, care teams and managers of health and social care services. One or other model, or a combination, prevails on any particular occasion, depending on the context in which interactions take place. much of the time models and concepts are implicit in conventions, norms and discourse rather than explicitly stated (Skultans 2007).

given that there are so many different ways of explaining or viewing 'psychosis', it is not surprising that there can be, and often are, disagreements about diagnosis. The differential diagnosis between Asperger's syndrome and schizophrenia generates a particular version of controversy, which appears in my experience, to be largely about professional territory, though this is probably not the whole story. The controversy probably also exists because this blurring of supposedly distinct diagnostic categories challenges the notion of schizophrenia as a coherent concept.

The process of addressing the controversy also challenges the conventional doctor-patient and doctor-carer/

relative relationships. In most cases it is the service-user's family who are of the opinion that Asperger's syndrome is the correct diagnosis, and who seek an independent assessment from an Asperger's specialist. This often results in lengthy disputes with clinicians who are of the opinion that schizophrenia is the correct diagnosis. In some cases legal proceedings follow in order to try to resolve the dispute.

The misdiagnosis of Asperger's syndrome

Autism and mental health is currently the topic of a campaign by the National Autistic Society (NAS 2010b). Published information about the mental health problems experienced by people with Asperger's syndrome demonstrates that these problems are a common complication of the condition (Andrews 2006; Berney 2006; Carpenter 1999, 2007; Farrugia and Hudson 2006; ghaziuddin 2005; RCP 2006).

A recent NAS paper about mental health and Asperger's syndrome states that:

People have been diagnosed as having schizophrenia when, in fact, they have Asperger's syndrome. This is because their 'odd' behaviour or speech pattern, or the person's strange accounts or interpretations of life, are seen as a sign of mental illness, such as schizophrenia. Obsessional thoughts can become quite bizarre during mood swings and these can be seen as evidence of schizophrenia rather than the mood disorder they actually are. (NAS 2010a)

This illustrates how the way a person's behaviour is interpreted can lead to the wrong diagnosis if the clinician giving the diagnosis does not have a good understanding of Asperger's syndrome.

The Asperger's syndrome specialist, Judith Gould (Director of the NAS Lorna Wing Centre for Autism) referred to the problem of people with Asperger's syndrome being misdiagnosed with schizophrenia in two recent presentations (gould 2010a, 2010b). She said that 'mis-diagnosis creates serious problems and can lead to months or years of treatment for a mental health disorder unnecessarily' (2010b).

Several studies have been carried out to identify patients in psychiatric hospitals (Hare et al 2000; Shah et al 1982) and in psychiatric outpatient settings (Chang et al 2003; Nylander and Gillberg 2001) who qualify for a diagnosis of autism and who have been misdiagnosed with another disorder. A study of the prevalence of Asperger's syndrome in Broadmoor high security hospital (Scragg and Shah 1994) found that this condition was more prevalent amongst the hospital patients than in the general population. Another paper (Murrice et al 2002) presents six case studies of individuals with Asperger's syndrome in forensic settings and discusses the role that the person's autistic characteristics played in their offending.

A recent study (currently under review) by David Mandell and colleagues at the Center for Autism Research in Philadelphia concluded that adults with autism are overrepresented and under-diagnosed in the psychiatric hospital where the study took place. Patients who qualified for a diagnosis of autism were, in almost all cases, misdiagnosed as having schizophrenia (personal communication with David Mandell).

Compounding problems by inappropriate treatment

A significant problem for those who have the high-functioning

form of autism called Asperger's syndrome is that their behaviour is more likely to be criminalised because their autism is not immediately apparent to an observer. They are more likely to be categorised as normal people behaving wrongly than disabled people for whom allowances should be made. The last paragraph of the paper by Hare and colleagues sums up one of the main reasons why the studies cited above have been carried out:

It must be emphasised that, for some, perhaps many, individuals with autistic spectrum disorders who commit offences, early diagnosis and appropriate care and education in childhood, and help and support in adult life, would have prevented the psychological confusion and distress that led to the crime being committed. (Hare et al 2000:19, section 5-1.12)

The researchers who carried out these studies did so to collect evidence to support the aim of providing the kind of support that will prevent people with autistic spectrum disorders behaving in ways which are regarded as criminal.

This issue of the criminalisation of distress illustrates how serious the consequences can be when a person with Asperger's syndrome does not get the support s/he needs during childhood and the transition to adulthood. The 'psychological confusion and distress' referred to in the quote from Hare et al. can be exacerbated by the use of medication, in some cases, if the underlying condition of Asperger's syndrome is not recognised and managed appropriately.

A film made in France in 2007 illustrates the disastrous outcome for one individual whose Asperger's syndrome was misdiagnosed as schizophrenia. *her name is sabine* is a documentary by the actress Sandrine Bonnaire about her sister. It uses an archive of family videos intercut with new material. In her late-teens Sabine was a vibrant young woman who had the features of Asperger's syndrome, though it was not diagnosed at the time. Two decades later, after coercive treatment in psychiatric hospitals including the use of medication over many years, Sabine is severely cognitively impaired and prone to aggressive outbursts. By then she also had a diagnosis of autism but, although she is now receiving good quality care, it is too late to reverse the cognitive damage which was almost certainly caused by medication. The film is sensitive and moving, but the overall message is a chilling portrayal of how damaging psychiatric treatment can be.

Misdiagnosis and medication

The studies of misdiagnosis of Asperger's syndrome referred to above demonstrate that misdiagnosis occurs, but they do not go beyond that in terms of discussing how the misdiagnosis and the subsequent treatment have affected the service user. These studies remain within the conventional biomedical discourse of mainstream psychiatry by using a style of expression that treats the concept of schizophrenia as valid, and the use of neuroleptic medication as the accepted course of action.

There are different treatment implications depending upon whether a person's primary diagnosis is considered to be Asperger's syndrome or schizophrenia. For Asperger's syndrome, the received wisdom is that there is no medical treatment for the condition itself (though mental health problems associated with the condition might sometimes be

helped by medication (RCP 2006). Appropriate care involves helping the person to manage the problems they have with social interaction and communication. Schizophrenia is commonly believed to be a treatable medical disorder for which neuroleptic drugs are the treatment, but of course many people disagree with this view and see the medication as a means of social control disguised as medical treatment (e.g. Double 2006; Szasz 2008).

The response of families to misdiagnosis and mistreatment highlights the way in which treatment might have compounded a service-user's problems. Two cases in the news in recent years are those of Piers Bolduc, who spent thirteen years in Broadmoor due to a lack of suitable services for a person with Asperger's syndrome (Barclay 2007), and Harry Horne-Roberts, a twenty-year-old artist who had a diagnosis of autism, who died after being given the neuroleptic chlorpromazine (gruner 2009; Stone 2009). The references cited here are items from newspaper, radio and the internet, which all include parents' accounts of how their sons have been seriously mistreated by the mental health and/or criminal justice systems.

Evidence for the detrimental effects of neuroleptic medication

There is no shortage of material to support the view that neuroleptics have detrimental effects. These concerns are backed up by another recent account in the media. Panorama (BBC 1, November 1st 2010) reported on the use of neuroleptic medication for the elderly. This programme included the following statement from Paul Burstow, minister for Care Services: 'These drugs cut people's lives short.' Also on the programme was the psychiatrist Tim Kendall, Director of the National Collaborating Centre for mental Health, who emphasised that neuroleptics should be used only as a 'last resort' and 'for a limited time only'. This contrasts dramatically with how these drugs are actually used in many psychiatric units: it is standard practice to keep people on drugs indefinitely. Although the Panorama programme was about the elderly, younger people who are currently on neuroleptics will one day be old, and by that time they will have been on this medication for several decades.

There is an extensive and growing literature on the damaging effects of psychiatric medication, in particular neuroleptics, which supports the concerns expressed by people whose Asperger's syndrome has been misdiagnosed, and by their families. A few examples illustrate the range of material.

Joanna Moncrieff's work at University College London shows that there can be iatrogenic 'withdrawal-induced adverse effects' in the form of 'supersensitivity psychosis' when discontinuing neuroleptic medication (Moncrieff 2006). A systematic review of the effects of neuroleptic drugs on brain-volume concluded that there is evidence to suggest that these drugs 'reduce the volume of brain matter ... and may contribute to the genesis of some of the abnormalities usually attributed to schizophrenia' (Moncrieff and Leo 2010). The clinical psychologist Richard Bentall's book *Doctoring the Mind* is an indictment of the foundations underpinning psychiatric treatment (Bentall 2010). Researchers from the University of Coventry and the West Midlands Care Services Improvement Partnership (Tummey and Tummey 2008) discuss iatrogenic abuse in standard psychiatric practice. The psychiatrist Peter Breggin (2009)

argues that there is a link between the use of neuroleptic medication and violent behaviour and crime. The link between neuroleptic drugs and reduced life-expectancy due to increased cardiovascular risk is established in a study from the University of Greifswald in Germany (Weinmann and Aderhold 2010). 'Unexplained deaths' in relation to post-mortem concentrations of neuroleptic drugs are discussed in a study from the Institute of Psychiatry in London (Jusic and Lader 1994). A convincing argument that neuroleptics do more harm than good, and that they have contributed to an increase in mental illness, is presented by the American writer Robert Whitaker (2004, 2010).

It is hardly surprising that the new genre of research known as 'survivor research' provides accounts of those who have managed to move on from conventional psychiatric treatment (e.g. Sweeney et al 2009). Survivor research provides first-hand accounts of being on the receiving end of treatment. It also gives hope and optimism about the potential for full recovery from mental health problems and new possibilities for mental health practice (Bracken and Thomas 2005).

Bringing information together in current research

The above discussion shows there are two separate bodies of literature which are both relevant for examining the overlap between Asperger's syndrome and schizophrenia, but which so far do not 'speak to each other'. Literature on the misdiagnosis of Asperger's syndrome does not include information about the effects of neuroleptic medication, and does not overtly question the biomedical paradigm of mainstream psychiatry. Literature about the detrimental effects of these drugs does not address their use for people with autism. From a lay perspective it is clear that both kinds of literature are important, and that it would be useful to integrate the findings from both strands of research. I am currently working on this as part of a study about service-user and family views on the overlap between the two diagnoses.

My work is funded by the Wellcome Trust. It involves discussions with families and their relatives who have been diagnosed with both Asperger's syndrome and schizophrenia. In most cases the service users and families to whom I have spoken view their situation as the misdiagnosis of schizophrenia for Asperger's syndrome. Their health and social care professionals do not always share this view. Concern about the negative effects of neuroleptic medication is a recurrent theme in the views expressed by families and service users, and the problem is compounded by inappropriate care and treatment. This illustrates the need for a review of both kinds of literature presented above.

The material I have referred to so far illustrates that existing research about the misdiagnosis of Asperger's syndrome as schizophrenia mostly focuses on hospital settings, including secure psychiatric units. There is no research on this issue from lay perspectives, and no research spanning services across community and in-patient contexts. The aim of our study is to fill both these gaps in the research literature and in current understandings of this overlap between the two diagnoses. Ultimately, the aim of the research is to contribute to improving the well-being of people who have, or have had, both diagnoses, by making recommendation for service-provision whilst taking account of the views of service users and their families.

Implications for the concept of schizophrenia

My research focuses on the experience of individuals who have, or have had, the diagnosis of schizophrenia (with Asperger's syndrome), but this will inevitably extend to other diagnoses as well, such as schizo-affective disorder, bipolar disorder, and other psychoses. It is common for a person's diagnosis to change over time, as s/he is assessed by different clinicians or as his/her presentation changes. Therefore, the focus on the category schizophrenia is simply a starting point for looking at how the combination of Asperger's syndrome and psychosis is labelled and interpreted.

It seems likely that this research about lay perspectives on the overlap between the two diagnoses will contribute to deconstructing the notion of schizophrenia in a way that will support the view, expressed by the Campaign for the Abolition of the Schizophrenia Label (CASI), that the term is redundant. The Asperger's syndrome perspective on 'psychosis' is, in many ways, similar to the PTSD (post-traumatic stress disorder) view of 'psychosis'. Both present an explanation or interpretation of this state as being a natural and predictable reaction to persistent trauma, a manifestation of extreme distress that can be reversed if circumstances change.

• • •

I am interested in hearing from anyone who has experience of living with both these diagnoses, whether service users or family members/carers. Please contact me if you would like to participate in the research, or would just like to discuss the aims and ideas of the study: 078 1667 0088 or alison.tierney@bristol.ac.uk .

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The Case against Schizophrenia

2011 marks the one hundredth anniversary of the introduction of the diagnosis of schizophrenia by the Swiss psychiatrist Eugen Bleuler.¹ In this article we propose that the best way to celebrate this event is to consign the diagnosis to history. In doing so we declare our support for the position already set out by the Campaign for the Abolition of the Schizophrenia Label (CASL). This argues that there is no longer any justification for the continued use of the diagnosis because the way it is used is both unscientific and harmful.²

We endorse CASL and present additional information in support of their position. There are three main arguments against the current use of the diagnosis of schizophrenia: it has no scientific basis, it is harmful, and it leads to stigma.

Although they still retain the overall concept, it is worth noting that the latest thinking from the American Psychiatric Association suggests that there may be no place for sub-types of schizophrenia in the latest *Diagnostic and Statistical Manual (DSM-V)*.³ The arguments we develop here are specifically directed at the diagnosis of schizophrenia. We are not proposing the complete abandonment of diagnosis, but psychiatric diagnoses really need to be recognised for what they are: simply working concepts for clinicians justified (or not) by their clinical utility.⁴ The problem is that the label 'schizophrenia' has lost any such value because it proposes so-called 'cut-and-dried facts' about psychological conditions and mental health treatments that simply do not stand up to scrutiny.

The diagnosis of schizophrenia has no scientific basis

There have been many excellent and thoughtful scientific critiques of the concept of schizophrenia.⁵ Over the last thirty years or so, academic psychiatrists worked hard to improve the reliability of psychiatric diagnosis, partly in response to critics who pointed out that the diagnosis of schizophrenia was meaningless due to poor levels of agreement between psychiatrists about the key symptoms; psychiatrists were also actually unable to discriminate reliably between the sane and the insane.⁶ In response, *DSM-III* and *DSM-IV* tried to impose diagnostic agreement throughout the profession by the use of check-lists of diagnostic criteria. But this only served to highlight an even more fundamental problem with the concept of schizophrenia: its validity.

The philosopher Carl Hempel argued that the validity of a concept like schizophrenia depends upon the extent to which it represents a naturally occurring category. If it does so, then there should be an identifiable biological property of those who have the diagnosis, making them distinct from those who don't: the category really ought to 'carve nature at the joint'.⁷ The failure of research to reveal a single, specific biological abnormality that distinguishes those diagnosed as having schizophrenia from those who are not indicates that categorical diagnostic systems such as *DSM-IV* and *ICD-10* have outlived their usefulness.⁸ Even genetics researchers now argue that the categorical diagnosis of schizophrenia severely handicaps their studies.⁹

A central feature of diagnosis in medicine is that it should predict the future course of the disease if left untreated (its natural history), as well as the response to specific forms of treatment. In 1913, Kraepelin reported that only 13% of his patients recovered from dementia praecox (soon to be called 'schizophrenia').¹⁰ But evidence from more recent long-term outcome studies of patients shows that in broad terms 50% or more of diagnosed schizophrenics improve significantly, and many make a full recovery.¹¹ This is confirmed by recent work in Singapore and Madras: Kua found that two-thirds of

schizophrenic patients in Singapore had a good or fair outcome at 20 years;¹² in Madras, Thara found that, over twenty years, only 5 out of the 61 subjects followed up had been continuously ill, whilst more than three-quarters were in employment.¹³ There is simply no evidence to support the view that the diagnosis of schizophrenia predicts a poor outcome.

Moreover, there is no evidence that there are any specific biological treatments for schizophrenia. Although antipsychotic drugs are sometimes claimed to reverse a biochemical imbalance, no such imbalance has been demonstrated. The drugs are more likely to work through their general suppressant effects, which they exert in anyone who takes them and not just people diagnosed with schizophrenia.¹⁴ Claims about the causes and treatments of the condition are not only unscientific but positively impede recovery.

The diagnosis of schizophrenia is harmful

Some people appear to be happy to receive a diagnosis of schizophrenia. It is one way in which they can 'make sense' of their experiences.¹⁵ However many find it unhelpful.¹⁶ A large-scale study in nearly thirty countries involved face-to-face interviews with over 700 people diagnosed with schizophrenia. It reported that 54% felt that the diagnosis had been a disadvantage.¹⁷ Similar findings emerge in the personal stories of those diagnosed with schizophrenia.¹⁸ In our view there are four main reasons why the diagnosis of schizophrenia can be harmful: it impedes recovery; it denies the importance of meaning; it makes people feel powerless; it obscures the importance of the contexts to psychological crises.

The diagnosis obstructs recovery

We speak of people recovering from cancer or open-heart surgery: the word 'recovery' is tied to the medical model. But for many survivors and service users the word has a different meaning, one that implies speaking out, an act of reclamation, or as Coleman puts it, 'having a voice'.¹⁹ There can be no story and no recovery without a language to speak, a voice to speak with and opportunities to be heard by others. Through its own social action, the psychiatric survivor movement has created safe spaces in which individuals can start the process of telling their own stories. The point is that the meaning of recovery for service users and survivors in Britain²⁰ and in the USA²¹ is very closely tied to the struggle of those people to have the right to tell their own stories in their own way.

As far as recovery is concerned, the real problem with the diagnosis of schizophrenia is that it imposes a narrative of despair on those it identifies. Robert Barrett, an Australian psychiatrist and anthropologist, examined the cultural preoccupations which shaped the origins of the concept of schizophrenia in the late-nineteenth century.²² One was the contrast between the integration and disintegration of the individual. Another was a concern with the Enlightenment ideal of progress and its opposite, degeneration. Both had a great influence on the emerging discourse about schizophrenia. This influence persists to this day. It can be seen in the false belief that schizophrenia is a condition that inevitably has a poor prognosis, and from which the chances of recovery (*restitutio ad integrum*) are slim. It is to be found in psychiatric talk about 'deficits' and 'defect state', and embodied in mental health services whose purpose is to ensure the rapid and early drug treatment of young people in their first episode of psychosis, so as to prevent 'deterioration'. These are narratives and rituals of hopelessness and despair.

The diagnosis forecloses meaning

A mental health diagnosis like 'schizophrenia' obliterates meaning by transforming significant experience into a narrow framework of 'disease'. Louise Pembroke found that when her psychiatrist diagnosed her as schizophrenic he not only disregarded her own spiritual understanding of her experiences but made a problem of it by regarding it as yet another symptom of her illness.²³ O'Hagan describes how her psychiatrist's preoccupation with diagnosis and medical treatment meant that he turned away from her actual suffering and failed to engage with it.²⁴ The requirement to render psychiatric patients' experiences into the terms of a categorical medical diagnosis means that many of the most complex and important experiences of distressed people are stripped of all meaning by identifying them as 'nothing but symptoms'.

On the other hand, Brunner was finally able to understand her psychosis in terms of her mother's experiences of madness after moving from Jamaica to England in the 1950s, and through their shared experiences as black women in a predominantly white culture.²⁵ Likewise, Dewan was able to understand her psychosis in terms of the problems generated by her mixed cultural heritage (Indian and Irish Catholic).²⁶ Racism features prominently in these women's understandings of their psychoses. They contrast their own contextualised understandings with the usual reductive psychiatric diagnosis (in terms of disordered brain function which simply requires medication). This is particularly significant in the light of much evidence that in Europe and the USA African and African-Caribbean people are far more likely than whites to be diagnosed as suffering from schizophrenia.²⁷

The diagnosis makes people powerless

Peter Campbell saw the power of psychiatry in terms of the influence and control it had in so many areas of his life.²⁸ Although Peter's psychiatric diagnosis was 'manic-depressive psychosis', his experiences reflect those of people diagnosed with 'schizophrenia'. He makes two points about the power of psychiatry. First, the judgment that a person 'lacks insight' is profoundly disempowering, especially when 'having insight' means agreeing that you suffer from schizophrenia. To say that someone lacks insight is not to state a fact but to make a judgement, one that reduced him to a '... category of persons whose experience is devalued, status diminished and rational evidence dismissed ...' (p. 57). Secondly, diagnosis, and the biomedical model it implies, is the dominant framework through which society interprets psychosis. This has two implications: it means that people only really talk about recovery in terms of symptoms-control – which many service users find very unhelpful; and it contributes to society's predominantly negative view of those who experience psychosis. We will return to this shortly.

The diagnosis ignores or obscures contexts

We have already seen that the use of the diagnosis of schizophrenia pays scant regard to cultural contexts and personal narratives which are always rooted in a particular context. However, the contexts that we are particularly concerned with are those involving experiences of abuse and trauma. This is important because there is now a substantial body of evidence linking the experience of hearing voices and other psychotic experiences to trauma and abuse of adults and children.²⁹ This evidence resonates powerfully with the experiences reported by members of the Hearing Voices Network. Speaking at a conference in Manchester in 2006, the National Chair of the organisation described how it had listened to the experiences of people who hear voices for fifteen years. Many of these people had been diagnosed as schizophrenic, but their experiences included sexual, physical and racial abuse, poverty,

neglect and stigma.³⁰ This is why it is so important to attempt to understand psychotic experiences in the context of the story of the person's life. In fact, it is harmful not to do so since this obscures and mystifies the origins of problematic experiences and behaviours which could otherwise be understood.³¹

The diagnosis of schizophrenia leads to stigma

It is widely believed that improving public understanding of schizophrenia in biomedical terms will improve public attitudes towards people with the diagnosis, and thus reduce stigma. This is because it is assumed that if the causes of psychosis are attributed to biological factors over which the person has no control, then the individual cannot be blamed or held responsible. In fact recent research evidence refutes this view. Using vignettes of schizophrenia and depression, researchers subjected to a trend analysis two representative population surveys of public attitudes to psychiatric patients conducted in the Länder of the former German Federal Republic in 1990 and 2001. Over this period, an increase in public acceptance of biomedical explanations of psychosis was associated with a public desire for increased distance from people with schizophrenia. This trend did not hold for 'major depressive disorder'.³²

So as to assess whether the idea that 'schizophrenia is an illness like any other' helps reduce prejudice towards those with the diagnosis, Read et al. made a comprehensive review of the literature on stigma and schizophrenia. The authors found an increase in 'biological-causal beliefs' across Western countries in recent years: this approach is gaining in popularity. However, biological attributions for psychosis were overwhelmingly associated with negative public attitudes in 18 out of 19 studies, whereas psychosocial attributions were associated with positive attitudes in 11 out of 12 studies. Biological attributions are thus strongly linked to negative public attitudes, i.e., stigma. This appears particularly the case for the diagnosis of schizophrenia.³³

Sayce has described in detail the implications of stigma, particularly the loss of citizenship rights associated with being a psychiatric patient.³⁴ It is known that the label 'chronic schizophrenia' interferes with a person's identity and biography.³⁵ In addition, the more a diagnosed schizophrenic expresses conventional 'insight' into his condition, the lower his self-esteem and the greater his feelings of despair and hopelessness.³⁶ 'Insight' also predicts higher levels of depression and risk of attempted suicide four years later.³⁷ Other researchers find that the presence of 'insight' correlates negatively with emotional well-being, economic satisfaction and vocational status.³⁸

Accepting a diagnosis of schizophrenia involves the person having to accept the negative public attitudes and stigma associated with that diagnosis. As we have seen, the diagnosis brings expectations of a gloomy outlook with lifelong dependency on psychiatric treatment and little chance of complete recovery. Hence rejecting the diagnosis – i.e., 'lack of insight' – may be understood as a positive way of coping with the implications of the diagnosis for personal identity.

In conclusion

There are three major objections to the continued use of the diagnosis of schizophrenia: It has no scientific basis, it is harmful, and it increases stigma. An important aspect of the harm is the obstruction to recovery: it prevents people from finding meaning in the psychosis; it invokes powerlessness; it disregards personal contexts of trauma and abuse.

Psychiatric diagnosis is not a scientific-medical project like any other: it involves much more than simply 'carving nature

at the joint'. With regard to so-said 'mental illness' – that is not real, organic illness, but emotional and psychological distress – diagnosis does not identify disease. What is required is to understand the reasons for actions. The value-laden nature of psychiatric diagnosis is a sign of the importance of intentions and meanings to therapy. The false assumption that schizophrenia is some kind of 'thing' (an actual disease) blinkers people to important clinical features of diagnosis, especially those narrative aspects necessary to tease out the different meanings of suffering – from the perspectives of the patient, the family and the clinician.

There can be no justification for the continued use of a diagnosis like 'schizophrenia'. It is unscientific, it serves to obscure the meaning of psychosis, and it is harmful. We fully support the Campaign for the Abolition of the Schizophrenia Label, and will work with them and others committed to getting rid of it. The onus is on clinicians and academics in the field of mental health to work much more closely with service-users and carers, so as to find more acceptable ways of identifying and helping those suffering from a psychosis.

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What has one hundred years of schizophrenia done for humanity? Was it a hundred years of enlightenment or one hundred years of solitude? Do we know more or less than we did then about the brain – or is it the soul we're talking about? I hope in a hundred years' time we'll look back at what is being done now in the name of mental *health* and realise how little the so-called experts knew or understood.

And what has the label 'schizophrenia' done for our family? I'll sum it up: a whole load of heartache, anger and frustration. When I cast my mind back more than ten years to when the word 'schizophrenia' first intruded into our lives, I was petrified. We'd just had to fetch our very frightened son from university. My husband entered a description of what we saw in him into a search engine and up popped all the 'symptoms of schizophrenia'. We really didn't know what to think or do. We knew nothing about 'it' or 'its treatment' apart from images of mad axemen, and poor tortured souls on the psychiatric ward where my brother worked as a nurse.

When my son was referred to the local community mental health service they didn't use the 'S word' straight away. In fact, they didn't use any terms at all, since no one spoke to me when I first took (or dragged) along our still terrified son to his first appointment with fear.

Over a year later it was recognised that my son's 'symptoms' were still very much present and weren't 'responding to the treatment'. Then I was taken into a room by a junior doctor and told that my son had 'it' and therefore I qualified to be referred to a Family Support worker.

The implications of why they were now using the term schizophrenia weren't really discussed with me. It was presented as a fait accompli, with no explanation of how or why they'd arrived at the diagnosis. I was expected to see this as a bonus for me since now I was officially allowed to talk to someone about 'It'. I remember being presented with a folder from a charity with helpful advice to families such as "Don't argue with your relative if they say something is there that isn't", "It's best to change the subject and avoid any confrontation", and "Whatever you do don't discuss the content of their delusions". There were lists of positive and negative symptoms which, to me, seem to have been put in the wrong columns. Our job as family members primarily seemed to be to ensure the person got his prescription and took his medication. There was no advice about how to challenge a diagnosis or its 'treatment'.

I remember spending hours talking with my husband about how to tell the rest of the family about this diagnosis and help them understand its consequences. Our parents' first reaction was "We must keep this to ourselves and not tell auntie and uncle." Perhaps the stigma the word holds had gripped them and they were really ashamed and frightened about other people's reactions. Now they couldn't be more supportive and loving grandparents to our son, but at the time their initial thoughts may have been of confusion or horror and shame.

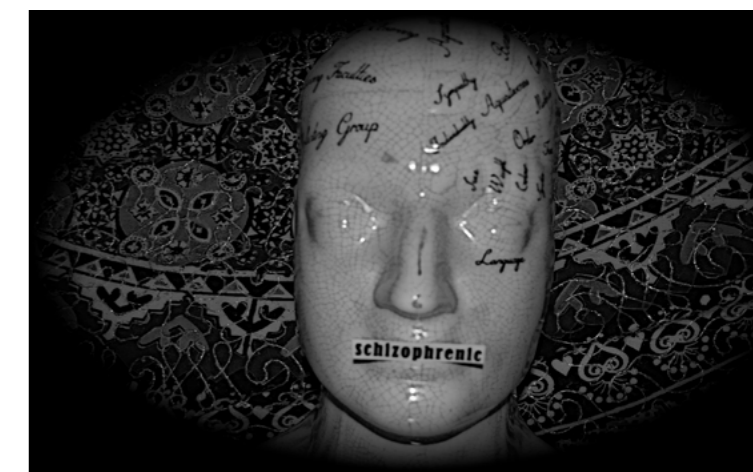
A few years later, when my son was in a so-called rehab unit many miles from home, when we went to pick him up for Christmas leave we eventually got to meet the psychiatrist. His first words were: "Hello, your son does have schizophrenia. I know because these are his symptoms." He went on to list things my son had never experienced. The psychiatrist ignored my son when he walked into the room. He didn't look at him or speak to him, but proceeded to tell us that he would always have to be on medication, would never be able to work, and there wasn't very much that could be done for him, really.

This must have been the worst Christmas present my son could have received because as soon as we arrived home he disappeared and was found, the worse for wear, many hours later. He wasn't in a fit state to discuss the whys and wherefores of his escapades that night. However, the next morning, Christmas Eve, as he arose bright and early to help with preparations and I asked him, "What was all that about, last night?" He replied, "Mum I just couldn't bear it when that doctor said I had schizophrenia and wasn't going to get better, so I thought I may as well go and have one last good night out."

When people realise my son is stuck in the psychiatric system they often ask me "What's his diagnosis?" I'm never able to give them a simple answer. I may change the subject, saying "He's got loads – which one would you like," or explain that I don't believe in diagnoses, and certainly not this one. In writing this article I'm even having problems writing the word. I certainly do find it almost impossible to say it in relation to my son – the word really doesn't want to leave my lips.

Why do I have such difficulty with 'the S word'? Is it the word itself, or the label and all it brings with it? When I looked in a search engine for definitions I found it very pessimistic. For example, 'A *psychiatric diagnosis denoting a persistent, often chronic, mental illness variously affecting behavior, thinking, and emotion.*' If I felt that if my own behaviour, thinking and emotions were going to be persistently or chronically affected I'm not sure I'd feel too happy about the prognosis. If I believed I was going to spend the rest of my life 'with significant social or occupational dysfunction' I'd probably feel like ending it all. When I discovered that 'The exact cause is unknown but it is believed to be caused by a biochemical imbalance', I began to wonder if the medical experts really knew what they were talking about.

Such simplistic definitions show that there is a huge lack of understanding of the real link between trauma and



psychosis in society as a whole. How can we expect families to seek the right kind of support, and feel optimistic about the future, if such unhelpful and damning statements are presented to them when they first try and find out what is happening to their relatives?

The Collins Dictionary gives: '*NOUN 1: any of a group of psychotic disorders characterised by progressive deterioration of the personality, withdrawal from reality, hallucinations, delusions, social apathy, emotional instability, etc. HISTORY C20, from Greek schizo split + phren mind.*'

I'm not sure which bit of that bald definition is the most distressing and hopeless. Perhaps it's the '*progressive deterioration of the personality*'. What hope there for recovery? Perhaps it's the fact that there is no attempt to explain how the listed characteristics arise – no attempt to make any connection between those cold, observable 'symptoms' and a human response to overwhelming experiences.

My son's response to being told he has this 'illness' is generally to become very angry. Frequently he emphatically states, "I'm not a schizophrenic, you know." He usually refers to having had a spiritual experience, and often describes seeing a golden light or "meeting the Holy Ghost". Sometimes he frames the change in himself as "when I had the kundalini rush" (a yogic term). When he talks about these ideas to the Responsible Clinician, I imagine this merely confirms their opinion that 'obviously he has schizophrenia'. Madness, in the sense of anger and frustration at being labelled and incarcerated, leads to more madness! The longer he stays locked into this diagnosis, the more angry and mad he becomes: a truly vicious circle.

I believe the term and the label only lead to more separation. Fear of madness and otherness can lead to people distancing themselves from someone with this diagnosis. It's as if society has decided, literally and metaphorically, to put 'it' and 'those people' over there. Sadly, there is still a sense of 'You have this illness/condition; I, thank goodness, don't and never will'. The label perpetuates a world of 'Us and Them'.

I have noticed this attitude even within the 'service user' world, where sometimes those who have been in a psychiatric hospital for depression, for example, make negative remarks about those with a diagnosis of schizophrenia. This especially seems to apply when trying to discuss the possibility of people becoming medication-free. When there are

campaigns to reduce stigma around mental health the examples used are usually people with a diagnosis of depression. If stories of 'schizophrenics' are quoted, it's still using the terms 'illness' and 'treatment', meaning medication. It can be even worse when people try to use euphemisms instead of the dreaded 'S word'. The phrase 'severe and enduring mental health



problems' must be the most devastating and pessimistic. Living with the knowledge that what's happening to them is never-ending may lead to some people to feel suicidal, and to many families giving up hope for their loved ones ever achieving independent and fulfilling lives.

Staff attitudes are often equally unhelpful. I once asked a nurse why she thought my son was running up and down the ward corridor at a time when he hadn't had any leave to go outside for several weeks. She replied "You see, it's because of his illness." She could not begin to understand how she would feel in such a situation. Similarly, members of staff often simply refuse to believe my son when he tells them the truth about his life: it was assumed to be a delusion caused by his illness when he described travelling and rock-climbing in South Africa.

The notion that schizophrenia is an illness requiring treatment by 'experts' in a hospital can prevent staff from taking into account his feelings and natural responses to difficult situations. A few years ago, during a Mental Health Act Review Tribunal, I was explaining the effects of medication on my son's emotions: they left him very flat and unable to respond to everyday situations or to recognise his feelings and link them with his actions. The psychiatrist's reply was categorical: "Being emotionally blunt is just a symptom of his illness and totally unrelated to the treatment." Yet so long as 'the usual treatment' for schizophrenia is anti-psychotic medication it is very difficult to disentangle 'the symptoms of an illness' from adverse reactions to the drugs.

So what can we do? Abolishing the label won't abolish the concept that goes with it, but a campaign to come up with a more meaningful and informed alternative form of words would be a good start. What we really need is to reframe the whole system so that it moves away from diagnosis and looks at what kind of responses might help individuals to make sense of what has happened to them. The only reason for a diagnosis is surely to decide upon appropriate treatment. (That is, apart from putting people permanently onto benefits. I think we may need a whole issue of *Asylum* to examine how the welfare system can marginalise people and trap them in a netherworld!) If 'the usual treatment' isn't working, should we not question the validity and purpose of diagnosis rather than blame the patient for being 'treatment resistant'?

There are some positive examples of groups working differently to show how more humane, insightful and respectful approaches to distress and extreme states of mind can bring about a recovered sense of self. One of these is the Soteria Network (soterianetwork.org.uk), part of an international movement of people genuinely interested in finding ways through madness to deliverance. 'Soteria' is Greek for



'salvation' or 'deliverance'.

I first became aware of this Network about seven years ago, when the founder of the first Soteria House, Loren Mosher, came to speak in Bradford. Although I missed him, he left such a buzz amongst those I know who care about changing the mental health system that I joined the UK Network straight away. Later I became a trustee of the organisation. In our local community, we are now working towards setting-up the first Soteria House in the UK. We have gathered together a group of people with a wealth of experience who meet regularly to plan how this house can provide evidence that people can be supported through their troubles in a safe environment, without medication, if they choose to be in the real world. We won't be using labels or diagnoses. Instead we shall come with an open mind, listening to their stories, learning from them and providing a respectful, compassionate and healing community.

We looked at the crucial elements of the Soteria model and saw that they match well with the WindHorse Project, with its principles of recovery. Because we wanted to set up as soon as possible, we decided in the first instance to open a very small rented house. This will be based on WindHorse, which uses the idea of 'basic attendance' support for just one person who is in an extreme state of mind. There will be two housemates and a team of volunteers, trained and supported by a paid coordinator.

In the current economic and political climate we are more likely to be able to go ahead with this project if we avoid applying for funding through the statutory sector. We want to ensure that it is led by a group genuinely grounded in the local community. Therefore we are being creative with fundraising, looking to a variety of sources. Last summer we organised a sponsored bed-push and cabaret, raising over £5000. We have a series of concerts coming up. And as soon as we have achieved full charitable status we plan to apply to a range of organisations for grants. One of the regular sources of income is through the Soteria website. If people wish to order goods from Amazon they can do this via our website and we gain 5% of the purchase price without costing them anything. So if you want to see the first Soteria House open in the UK, please support us in this way.

Once we have opened the first house, run it successfully and provided evidence showing that outcomes for people experiencing psychosis are better, in that they will be recovering to live meaningful, productive, drug-free lives and in a way that is less costly than the 'usual treatment', we expect those with influence and funding to sit up and take notice of us. We hope to open a range of houses, all following the Soteria model but meeting a range of circumstances and needs. My dream is eventually to open a house specifically to support those wishing to withdraw from neuroleptic drugs. If you share my dream then please support this project!

Join us at
www.soterianetwork.org.uk

I Don't Hear Voices

Lucy Gorecki

I don't hear voices –
Whatever do you mean?
My thoughts are processed and squeaky clean!
I don't hear voices –
I think you're out of line.
Don't think you can compare your reality with mine!

I am not ill,
Nor am I insane,
Although I am confused by your strange little game.
You are trying to trick me
Into telling you bizarre things.
It's not going to work.
You will not win.

You say I am responding
To 'unseen stimuli'.
You ask who I'm speaking to,
I answer "You – why?"
You do not believe me,
You tell me I'm not right.
I say "I'm tired – it's the middle of the night."

My thoughts are racing.
My mind feels weak.
I finally give in.
I finally speak.
I tell you all the horrors that I really do feel.
I tell you the truth –
I swear this is real!

I can see people watching,
Hear them teasing and taunting,
But all you can see
Is my sanity unraveling.
"Put her in hospital, she needs to be medicated,
She needs to be observed and severely sedated!"

I run from you
And defy your wishes.
You've confirmed all my thoughts,
You've confirmed my suspicions.
You are my enemy, one and the same.
You're playing with my mind –
This is your game!
You want to lock me up and take all my choices.

That is the reason why
I do not hear voices.

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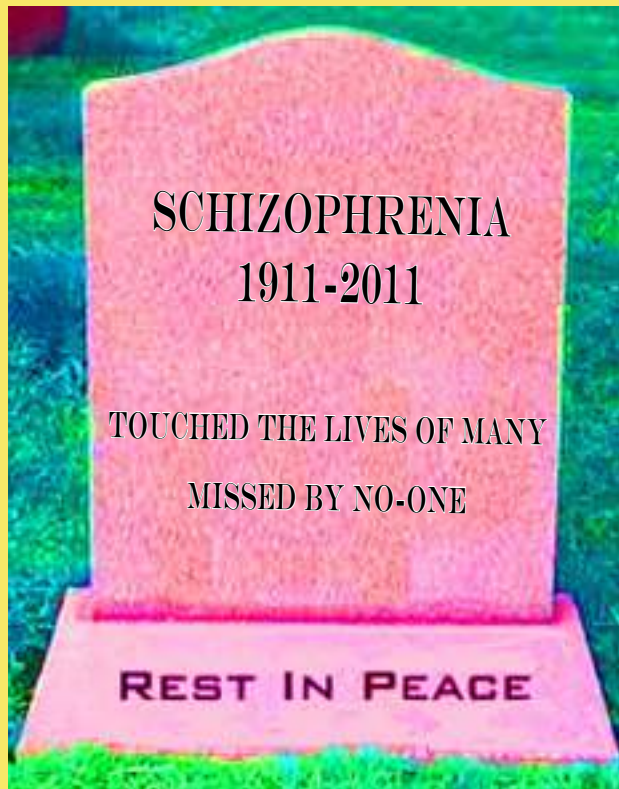
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