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### **Introducing CASL**

#### **The Campaign for Abolition of the Schizophrenia Label**

Paul Hammersley and Terence McLaughlin

***The idea that schizophrenia can be viewed as a specific, genetically determined, biologically driven, brain disease has been based on bad science and social control since its inception. If the scientific argument against 'schizophrenia' is judged to be won, it remains to take the evidence to the people, to explain and develop the alternatives in the full light of day. This is why the campaign is led by Asylum, the magazine for democratic psychiatry, psychology, education and community development. We believe the time is fully ripe for a paradigm shift across the field of mental distress and that the alternative knowledges and resources are now in place to mobilise for change. No more will we view the scandal where intelligent persons are expected to accept discredited diagnoses for fear of being labelled as 'lacking in insight' and having treatment forced on them.***

Read (2004) lists a fundamental dissatisfaction with the concept of schizophrenia as an illness that can be traced back over 80 years. More recently Bentall (1990, 2003), and Boyle (1990) have published elegant, well researched arguments clearly demonstrating that the concept of schizophrenia is neither valid nor reliable. Despite this, mainstream psychiatry continues to perpetuate the myth that when talking about 'schizophrenia' we are discussing something that actually exists. For example, the opening statement of the NIMH public information website in the USA reads as follows:

“Schizophrenia is a chronic and severe disabling brain disease”

As Read (2004) points out, such an opinion is common in psychiatric textbooks and drug company pamphlets.

The CASL campaign is driven by two central factors:

- 1) The concept of schizophrenia is unscientific and has outlived any usefulness it may once have claimed.
- 2) The label schizophrenia is extremely damaging to those to whom it is applied.

### **Reliability**

For a diagnosis to have any clinical utility it must be reliable. That is to say there must be consistency in how individuals are diagnosed. There is no evidence that this has ever been the case with schizophrenia. Read (2004), has illustrated how it is possible for 15 individuals with nothing in common to be gathered together in one room and ALL be diagnosed with schizophrenia. Test- retest analysis is as low as 37% and in 1970 when 194 British and 134 American psychiatrists were asked to provide a diagnosis on the basis of a case description, 69% of the Americans diagnosed schizophrenia whilst only 2% of the British did so. There is no definitive evidence to suggest that the reliability of the diagnosis has improved since that date.

### **Validity**

An unreliable diagnosis cannot by definition be valid. However it is worth pointing out quite how poorly the diagnosis of schizophrenia performs in terms of validity. Firstly, a diagnosis of schizophrenia tells us nothing about cause. Biological research into cause offers little more than a series of dead ends (Bentall 2003, Read 2004), and the significance of genetic inheritance in schizophrenia has been vastly overstated and is seriously methodologically flawed (Joseph 2004). Secondly, a diagnosis of schizophrenia tells us nothing about prevalence rates. It is often blandly asserted that schizophrenia has a prevalence rate of 1% in all societies. This is not true; there is a wide disparity of prevalence between rural and urban environments and different research has shown prevalence rates of between 0.33 and 15%. In addition a diagnosis of schizophrenia tells us little about the course of the illness. Kraepelin initially suggested that schizophrenia was a chronic deteriorating condition in all cases. We now know that all outcomes are possible from chronicity to complete recovery. Interestingly Marius Romme, the Dutch Psychiatrist, has argued that those most likely to make a complete recovery are individuals who reject or drop out of the psychiatric system.

### **Stigma**

To be labelled 'a schizophrenic' is one of the most devastating things that can happen to anyone. This label implies dangerousness, unpredictability, chronic illness, inability to work or function at any level and a lifelong need for medication that will often be ineffective (Whitaker 2005), but will usually cause unpleasant side effects. To champion the idea that schizophrenia is an illness just like any other (sometimes referred to as mental health literacy) makes the situation worse, in that it has been shown to increase amongst other things mistrust and a desire for social distance.

Sincere attempts have been made to rescue the word for humanity (Jenner et al., 1993) yet we have had to conclude that the continuation of the concept serves only the greed of Big Pharma in the pursuit of producing yet more 'magic bullets' The desire of our campaign to place the label 'schizophrenia' into the diagnostic dustbin, in which it most certainly belongs, is not based solely on the poor science that surrounds it but also on the immense damage that this label can bring about. A single word can ruin a life as surely as any bullet and schizophrenia is just such a word.

### **Japan abolishes schizophrenia?**

There is hope. In 2002 in order to remove the stigma and prejudice associated with the term schizophrenia, The Japanese Society of Psychiatry and Neurology renamed the condition. Their reasons were that the old term 'Seishin Buntreyso Byo' (mind- split disease) was ambiguous, had purely negative connotations and was in part related to the inhumane treatment of most people who carried the diagnosis (Sato 2006). The new term is 'Togo Shitcho Sho' (Integration disorder). It is defined not as a specific illness, but as a syndrome based on a stress vulnerability model, with many different

causes, symptoms and outcomes. This change was brought about largely by lobbying from service users and family groups, and has been welcomed by service users and families alike.

### **Alternatives**

Alternatives already exist. Given the high levels of trauma in the lives of individuals who experience psychosis (Read et al 2004, Hammersley et al 2003) Professor Marius Romme in The Netherlands has for a number of years called for a new diagnostic category of post-traumatic psychosis. Colin Ross in the United States has made a similar call for a category of Dissociative Psychosis.

Yet alternatives also exist outside the language of psychopathology (Parker et al, 1995; Romme and Escher, 2000). In recognising the role of language and being prepared to make a practical deconstruction of what it produces (in this case forms of pathology) is taking one step in enabling communities, through self help networks, to regain control and ownership of human experience. Romme and Escher have remained particularly faithful to the contribution of knowledge of 'experts by experience' and we remain firmly convinced that the future health of communities lies largely in the hands of organisations like the Hearing Voices Network and new initiatives like the Paranoia Network and depression dialogues. The hope and promise of radical change is not something to be relegated wistfully to a bygone age but is firmly on the agenda today (McLaughlin, 2003). Furthermore growing alongside CASTL is a widespread enthusiasm to form a European Association for Democratic Psychiatry as the mechanism to bring about decisive change in public policy, media activity and social attitudes.

The CASL campaign began as collaboration between The COPE Initiative at the University of Manchester, the Hearing Voices Network and supporters of Asylum magazine (Asylum Associates). We are working to build a broad coalition of service users groups and like minded professionals, with the aim of bringing a more coherent and humane diagnostic system to service users worldwide. Yet it is more than that. We are looking to a future when we can talk less of the associations for democratic psychiatry and more of the International Association for Democratic Communities.

### **JOIN TODAY**

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## FIRST COMMENTS

**Marius Romme Emeritus Professor of Social Psychiatry:**

**"We have known for quite some time that the concept of schizophrenia has no scientific validity. We now however have an alternative which is more helpful. It is time to challenge the old concept and leave it behind.**

**The old concept is harmful because, it is impossible to solve the problems of the patient diagnosed with this illness. We now not only know that the symptoms exist and the illness does not, but we now know more about where the symptoms come from. It is a false suggestion that the symptoms are the result of an underlying illness. The symptoms are partly a reaction to serious problems in the life of the person and partly a reaction towards other symptoms. Therefore attention should be given to the reality for the patient of his /her complaints and the background for each of them should be explored. Only then do we discover what the problems for the patient are, and only then we might be able to help solve those problems. When for example hearing voices is the complaint related to a serious problem in the person's life and the explanation of the person is that it is the voice of God, this can be a reaction on hearing that voice as an explanation. This in itself is not a symptom but a reaction to the strange overwhelming voice often with the metaphoric meaning of a needed spiritual power or a father figure, wanted or feared".**

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

**'In our experience, gained through more than 15 years running a national network, listening to people who hear voices, many of them living with a diagnosis of schizophrenia; it is clear that there is a definite link between traumatic life events and psychosis. On a daily basis, we hear terrible stories of sexual, emotional and physical abuse, and the impact of racism, poverty, neglect and stigma on peoples' lives. 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 peoples' resilience and capacity to survive, often against the odds. The reduction of peoples distressing life experiences into a diagnosis of schizophrenia means that they are condemned to lives dulled by drugs and blighted by stigma and offered no opportunity to make sense of their experiences. Their routes to recovery are hindered. Rather than pathologising individuals, we have a collective responsibility to people who have experienced abuse, to acknowledge the reality and impact of those experiences and to 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 become tomorrow's psychiatric patients."**