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Journal of Humanistic Psychology Special Issue on Diagnostic Alternatives

“But what about real mental illnesses?”

Alternatives to the disease model approach to ‘schizophrenia’

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### Abstract

The old dichotomy between ‘neurosis’ and ‘psychosis’ appears to be alive and well in the debate about psychiatric diagnosis. It is often suggested that while diagnostic alternatives may be appropriate for the relatively common forms of distress with which we can all identify such as anxiety and depression, psychiatric diagnoses remain vital for experiences such as hearing voices, holding beliefs that others find strange, or appearing out of touch with reality—experiences that are traditionally thought of as symptoms of psychosis. Such experiences are often assumed to be symptoms of underlying brain pathology or ‘real mental illnesses’ that need to be diagnosed or ‘excluded’ (in the medical sense of ruling out particular explanations of problems) before deciding on the appropriate intervention. This paper argues that this belief is misguided, and that far from being essential, psychiatric diagnosis has the potential to be particularly damaging when applied to such experiences. It describes an alternative perspective outlined in a recent consensus report by the British Psychological Society Division of Clinical Psychology (Understanding Psychosis and Schizophrenia [Cooke, 2014]) which has attracted significant attention in the UK and internationally. The report argues that even the most severe distress and the most puzzling behavior can often be understood psychologically, and that psychological approaches to helping can be very effective. It exhorts professionals not to insist that people accept any one particular framework of understanding, for example that their experiences are symptoms of an illness. This paper outlines that report’s main findings, together with their implications for how professionals can best help.

**Keywords:** psychosis, schizophrenia, mental illness, psychosocial models, alternatives to diagnosis, British Psychological Society

**“But What About Real Mental Illnesses?”****Alternatives to the Disease Model Approach to ‘Schizophrenia’**

The theme of this special edition is the limits of, and alternatives to the practice of diagnosis in the field of mental health. Some have argued that psychiatric diagnosis is merely a method of classification with no conceptual baggage: indeed DSM-IV was explicit that it was “neutral with respect to theories of etiology” (American Psychiatric Association, 1994, p. xviii). However, as other contributors have made clear, the origins, assumptions and implications of ‘diagnosis’ are closely linked to one particular approach to problematic feelings, experiences and behaviors, namely the ‘medical’ or ‘disease’ approach. Interestingly, DSM-5 makes no claim of theoretical neutrality (Tsou, 2015). Whilst highly contested (e.g. Johnstone, 2014; Kinderman, 2014; Read & Dillon, 2013) the disease model is so widespread in our society as to be unquestioned or ‘taken for granted’ (Andrews, 2014) by many. It views puzzling experiences and problematic emotional states as symptoms of ‘mental illnesses’ which can be diagnosed and treated in the same way as say, malaria or diabetes.

Many of us are keenly aware of the limitations of this approach with respect to experiences with which we can all identify such as low mood and excessive fearfulness, traditionally thought of as the ‘neuroses’ of depression and anxiety respectively. Despite appearing in diagnostic textbooks, these experiences are widely acknowledged to be often, at least in part, understandable reactions to life circumstances. However, the same does not necessarily apply to those experiences such as hearing voices, holding beliefs that others find strange, or appearing out of touch with reality, which are traditionally thought of as symptoms of psychosis. Many people, both lay and professional, believe that there remain some experiences which

are symptoms of illness, perhaps arising primarily from something going wrong in the brain (e.g. Frances, 2014). The archetypal such 'mental illness' is schizophrenia, and many otherwise critical commentators (e.g. Frances, 2014, Frith, 2015) are keen to distinguish it from more 'normal,' understandable psychological problems. The grounds for this distinction appear to be both theoretical (a belief that certain experiences are markers of underlying biological illness) and practical (a wish to ensure, for example, that the people concerned receive appropriate care and do not end up in unhelpful environments such as prison (e.g. Frances, 2014).

Despite its current dominance, this view has been subject to increasing challenges, particularly in the UK, where a body of work built up over the past 20 years (e.g. Bentall, 2003; Morrison 2001, Freeman et al., 2012) suggests that even the most severe distress and the most puzzling behavior can often be understood psychologically in the same way as 'normal' anxiety or sadness. Moreover, there is evidence that psychological approaches to helping can be very effective, and that psychiatric medication is not always needed (e.g., Garety & Freeman, 2013; Morrison, Hutton, Shiers & Turkington, 2012, Morrison et al., 2014).

This body of work acknowledges that there are many different theories as to what causes experiences such as hearing voices, and that the unique combination of interacting 'causes' is likely to be different for each person. The idea that these experiences are symptoms of illness, perhaps caused by some sort of chemical imbalance or other problem in the brain, is just one of the theories. Even though schizophrenia is arguably regarded as the archetypal 'mental illness,' there is no objective biological test for it such as a blood test or scan, and it remains essentially an idea. Indeed, when biological research indicates risk factors for (and therefore possible blood tests for biomarkers of) such experiences, these biological risk factors

tend to relate to patterns of psychological experience that cut across diagnostic boundaries (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013). Moreover, there is a vigorous debate about whether the very idea of ‘mental illness’ is meaningful or useful.

The issues most often debated include: a) the extent to which psychotic experiences can be separated from ‘normal’ ones, b) the frequency with which ‘normal’ as well as ‘ill’ people have certain experiences, for example hearing voices, c) the extent to which clinicians can agree on a diagnosis (reliability), d) whether mental illnesses such as schizophrenia are real ‘things’ (validity), and e) the advantages and disadvantages of seeing things as illness (utility) (see, e.g., Kinderman, Read, Moncrieff, & Bentall, 2013).

### **The 2014 British Psychological Society Report ‘Understanding Psychosis and Schizophrenia’**

The British Psychological Society (BPS) has taken a critical position with respect to psychiatric diagnosis, both in general and with respect to schizophrenia in particular. Its 2011 response to the American Psychiatric Association’s (APA’s) proposals for DSM-5 stated that:

clients and the general public are negatively affected by the continued and continuous medicalization of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences... but which do not reflect illnesses so much as normal individual variation...

This misses the relational context of problems and the undeniable social causation of many such problems (BPS, 2011, p. 2).

The BPS Division of Clinical Psychology (DCP), which represents the majority of psychologists working in mental health settings, has explicitly criticized current

systems of psychiatric diagnosis, suggesting that “there is a need for a paradigm shift in relation to the experiences that these diagnoses refer to, towards a conceptual system which is no longer based on a ‘disease’ model” (BPS DCP, 2013, p. 1). Recent DCP guidelines on language use suggest that psychologists “avoid the use of diagnostic language in relation to the functional psychiatric presentations” (BPS DCP, 2015, p. 2). Its suggested alternative is to adopt an individualised approach, ‘collaborative formulation’ (BPS DCP, 2011). Formulations explore the personal meaning of the events, relationships and social circumstances of someone’s life, and of their current experiences or distress. The person experiencing the difficulty works together with the professional to develop a hypothesis, or best guess, which can provide a basis for finding a way forward. Unlike a diagnosis, formulation is based on the assumption that however extreme, unusual or overwhelming the nature of that distress “...at some level it all makes sense” (Butler, 1998, p. 2: see also Lucy Johnstone’s article elsewhere in this Special Issue). Formulations are an answer to the ‘brain or blame’ dilemma mentioned below: they make sense of problems in a way that neither implies that people are to blame, nor that their problems are ‘all in the mind.’

A significant development was the publication in 2014 by the BPS DCP of its report *Understanding psychosis and schizophrenia: why people sometimes hear voices, believe things others find strange, or appear out of touch with reality, and what can help* (Cooke, 2014). The report, freely available to download from [www.understandingpsychosis.net](http://www.understandingpsychosis.net), summarized the current state of knowledge and debate in the field, together with relevant academic references, and outlined a psychological approach. It was written for service users (consumers), journalists and the general public as well as professionals, and attracted significant attention in the

UK and world media. The current first author (AC) was the editor of the report and the second author (PK) was a major contributor (Cooke & Kinderman, 2014, 2015).

The next section will summarize the motivation behind the report and its major messages.

### **Summary of content**

The report argues (*inter alia*) that hearing voices and feeling paranoid are common experiences, which can often be a reaction to trauma, abuse, or deprivation. Calling them symptoms of mental illness, psychosis, or schizophrenia is only one way of thinking about them, with advantages and disadvantages. The report summarizes evidence that there is no clear dividing line between ‘psychosis’ and other thoughts, feelings and beliefs (e.g. Verdoux & Van Os, 2002): psychosis can be understood in the same way as other psychological problems such as anxiety or shyness (e.g. Freeman, 2007; Freeman et al., 2012; Morrison, 2001). Whilst acknowledging that for some people experiences of psychosis can be life-long and disabling, and that offering help to those affected needs to be a major national priority, the report also reminds us that for many people such experiences are short-lived. Even people who continue to have them nevertheless often lead happy and successful lives (Slade, Amering & Oades, 2008).

Turning more specifically to the issue of diagnosis, Understanding psychosis and schizophrenia acknowledges that some people find it useful to think of themselves as having an illness. But others prefer to think of their problems as, for example, an aspect of their personality which sometimes gets them into trouble but which they would not want to be without (see e.g. The Icarus Project, 2013). In what is perhaps its key message, the report exhorts professionals not to insist that people accept any one particular framework of understanding, for example that their



experiences are symptoms of an illness. Even the title of the report was a matter of some debate, for example whether the word 'schizophrenia' should be in intervened commas or even used at all. In the end we decided that it was necessary in order for the report to come up in internet searches, but that it was important also to have a subtitle demystifying the term.

After diagnosis the report moves on to implications for intervention, summarizing research suggesting that psychological therapies can be very helpful for many people who experience psychosis (see, e.g., Morrison et al., 2014), including those who choose not to take medication. However, only a small minority of those affected are able to access psychologically informed services, with the vast majority still being told that they have a mental illness and offered only medication (Schizophrenia Commission, 2012). Whilst many people find that neuroleptic drugs help to make the experiences less frequent, intense, or distressing, there is no evidence that they correct an underlying biological abnormality. More generally, it is vital that services offer people the chance to talk in detail about their experiences and to make sense of them. Despite this being what most people think mental health services offer, surprisingly few currently do.

Turning to the issue of causation - etiology, in medical language— Understanding psychosis and schizophrenia presents evidence that psychosis is often related to experiences of abuse, deprivation, victimization and racism (e.g. Fearon et al., 2006; Varese et al., 2012). There is also racism in services: people from black and minority ethnic communities are more likely than others to be diagnosed with schizophrenia (e.g., Delphin-Rittmon et al., 2015; see also Metzl, 2009), more likely to experience compulsion (Care Quality Commission, 2011) and less likely to be offered psychological therapy (Mind, 2013). The report therefore argues that services

need to change radically, and that as a society we need to invest in prevention by taking measures to reduce abuse, deprivation and inequality.

### **Problems with the idea of ‘schizophrenia’**

Drawing on the BPS report, but also on other sources, we now address the question: How meaningful or useful is it to conceptualize the experiences described above as symptoms of diagnosable ‘mental illnesses’ such as schizophrenia? Similar arguments apply to other ‘mental illness’ diagnoses such as bipolar disorder (see e.g. Jones, Lobban & Cooke, 2010)

### **The continuum: ‘psychotic’ experiences cannot be separated from normal ones**

It is often assumed that there is a discrete, identified disease process (most commonly ‘schizophrenia’) underlying experiences such as paranoia or hearing voices. However, evidence suggests that there is no straightforward dividing line between ‘mental health’ and ‘mental illness’ (normality and abnormality). Instead, there appears to be a continuum between good and poor mental health along which we all move up and down throughout our lives (Cromby, Harper, & Reavey, 2013; Verdoux & Van Os, 2002). At different times we may be more or less anxious, depressed, or suspicious, for example. Such feelings and beliefs often develop in response to stressful life events and are moderated both by the degree of support available to us and by the opportunities we have to make sense of what is happening (Andrew et al., 2008). The tendency to hear voices or to experience suspiciousness or paranoia also varies between individuals as part of a spectrum of complex personal traits and characteristics in the population (Bentall, 2003). On a number of dimensions, people range from being conventionally ‘normal’ to quite unusual. For example, most of us hold beliefs that some others find odd, but sometimes these beliefs are relatively common (for example, in Western society, the belief that Jesus

was divine or that mediums can communicate with the dead) and sometimes quite unusual (for example that a particular mark on our skin was put there by aliens and is highly significant).

This 'continuum' view is widely accepted with respect to experiences such as anxiety. Individuals differ in terms of how anxious they are in general. This may be an enduring characteristic of their personality, and is likely to involve a combination of genetic factors and upbringing. Only a minority will ever experience extremes of anxiety such as a series of panic attacks, which are recognized in the diagnostic textbooks as justifying a diagnosis of panic disorder. Similarly, there is evidence that the state of extreme suspiciousness commonly known as paranoia is an extension of the feelings of suspiciousness that we all feel from time to time (Freeman et al., 2005). People differ in this regard: everyone knows people with whom we have to be very careful what we do or say lest they interpret it as an insult. Similarly, situations vary in their tendency to provoke suspiciousness. We have all been in situations where it makes sense to be extra vigilant, for example walking home alone late at night; in such situations it is easy to be frightened by even the most innocent things. A quote from a member of the public (quoted in the BPS [2014] report) illustrates this point:

I felt quite lonely and isolated at school. Even though I had a few friends, I still felt left out and I remember that I started to think that when kids were laughing, that they may have been laughing at me. At the time I knew this was probably wrong, but I couldn't help it, and it started to make me feel even more uncomfortable around school... After university... probably as a result of being isolated again, the thoughts began to come back. However, this time I began to be under the impression that I had some sort of social handicap,

similar to autism, and that people could tell this just by the way that I did or didn't make eye contact with them. Consequently, going out on the street became an ordeal because the more self-conscious I felt about my eye contact, the more uncomfortable I felt when looking at people. Eventually, I was convinced that when I was out on the street, everyone who saw me instantly knew I had some sort of social handicap. It actually started to feel as if everybody who met me pretended to treat me normally and then laughed at me behind my back once I'd gone." (Adam, quoted in Cooke, 2014; p. 18)

### **Many 'normal' people have 'psychotic' experiences**

A second finding that casts doubt on the assumption that experiences such as hearing voices are necessarily part of an illness is that such experiences appear to be quite common. Many healthy, well-functioning people sometimes have 'abnormal' experiences. For instance, many people have heard voices at some point in their life (Beavan et al., 2011), and nearly one in three people may hold a belief that clinicians might consider paranoid (Bebbington et al., 2013). The latter authors concluded that "paranoia is so common as to be almost normal" (p. 425).

Only one in 50 people who have 'psychotic-like' experiences appear to meet DSM criteria for schizophrenia (Hemsley, 1993). Extreme circumstances such as sensory or sleep deprivation can lead to various disturbances, including paranoia and hallucinations in people who never previously had such experiences (Jackson, Hayward, & Cooke, 2011). Some people who experience visual or auditory hallucinations consider them spiritually enriching (Clarke, 2010; Heriot-Maitland, Knight, & Peters, 2012; Romme & Escher, 1993). There is huge diversity in the way that experiences are understood in different cultures. For example, cultures and subcultures vary with regard to whether particular experiences are seen as signs of

mental illness, as normal (religious and spiritual beliefs, for example), or even as revered gifts (Bhugra, 1996). These findings suggest that although psychotic experiences can be distressing and disabling for some, others experience them as helpful and life enhancing. Of course for many people they can be both, either at different times or even at the same time: a ‘dangerous gift’ (The Icarus Project, 2013).

It appears, then, that ‘psychotic’ experiences are more common than is frequently assumed and also shade imperceptibly into ‘normal’ ones. Turning to the remaining three points referred to above, there are also significant problems with the reliability, validity, and utility of the schizophrenia diagnosis.

### **The schizophrenia diagnosis is unreliable**

DSM-5 (APA, 2014, p.99-100) criteria for schizophrenia are as follows:

All criteria (A–E) must be met:

A. Characteristics: Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated). At least one of these must be (1), (2), or (3):

1. Delusions
2. Hallucinations
3. Disorganized speech
4. Grossly disorganized or catatonic behaviour
5. Negative symptoms (i.e. diminished emotional expression or avolition)

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence,

there is failure to achieve expected level of interpersonal, academic or occupational functioning).

C. Duration: Continuous signs of the disturbance persist for at least 6 months.

This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meets Criterion A (i.e. active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or by two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Ruling out of other disorders: Schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either a) no depressive or manic episodes have occurred concurrently with the active-phase symptoms, or 2) if mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.

E. Attributes: The disturbance is not attributable to the physiological effects of a substance (e.g. a drug of abuse, a medication) or another medical condition.

E. History: If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least a month (or less if successfully treated).

R reliability has been improved by the 'tick-box' approach taken by recent editions of DSM (APA, 1980, 1994, 2013) as exemplified by the criteria for schizophrenia outlined above. However it remains low (Carney, 2013), particularly in everyday clinical practice where diagnoses are often made without detailed reference to DSM criteria (Kirk & Kutchins, 1994). Clinicians tend to have diagnostic 'preferences' and people are often given a range of diagnoses during their contact with mental health services, as illustrated by these quotes taken from the BPS report:

I was labelled with all sorts: eating disorder not otherwise specified, major depressive disorder, borderline personality disorder, schizoaffective disorder and eventually schizophrenia...that was the one that knocked the stuffing out of me completely. What was the point in fighting if I was going to be suffering from a lifelong brain disease forever?"

(Sally Edwards quoted in Cooke, 2014, p. 12)

My psychiatrist gave me various mental health labels... She told me I had what was called 'schizophrenia' by the professionals. However, my mother, who had recently trained as a counsellor and well understood the ramifications of this, was concerned at the possibility of this becoming my diagnosis and the effect this might have on my long term life prospects. She asked the professionals to reconsider, and I was then told I had bipolar, which I later learnt is sometimes seen as being a slightly less (though not always much less) socially damaging diagnosis. I wonder if the professionals would have reconsidered in the way they did, had my mother had less wherewithal to challenge the establishment or had not spoken fluent English? I doubt it.

(Raza Griffiths quoted in Cooke, 2014, p. 22).

Diagnostic usage varies between different clinicians, hospitals, and countries. Even experienced clinicians who have been given extra training in applying the criteria only agree on a broad diagnostic category about 50% of the time (Kirk & Kutchins, 1994; Carney, 2013). The reliability of the schizophrenia diagnosis in the field trials prior to the publication of DSM-5 was particularly worrying (Cooper, 2014).

### **The schizophrenia diagnosis is invalid**

The tendency has always been strong to believe that whatever has a name must be an entity or being, having an independent existence of its own. And if no entity answering to the name could be found, men did not for that reason suppose that none existed, but imagined that it was something peculiarly abstruse and mysterious. John Stuart Mill, 1869

One argument that is often put forward by those who favor the idea of schizophrenia is that the experiences and behaviors that can lead to the diagnosis are very real. As someone said to us recently, "Just spend a couple of hours on my ward and you'll see beyond any doubt that schizophrenia exists."

It is of course true that experiences such as hearing voices are very real for the person concerned, and that they can lead both to distress that is very real and to behavior that is hard to understand. However, this does not mean that they are necessarily symptoms of real 'illnesses.' Giving something a name, and even being very clear about its definition, does not necessarily imply that it necessarily exists in reality. Most people would agree on how to identify a unicorn, for example, even though they are mythical rather than real creatures. The problem is that the existence of the label can give the misleading impression of the existence of the 'thing.' Van Os (2009) explains it in these terms: "The complicated, albeit ultimately meaningless,



Greek term suggests that schizophrenia really is a 'thing,' i.e. a 'brain disease' that exists as such in nature. This is a false suggestion (p. 368).

So the question at issue is the extent to which the label of 'schizophrenia' refers to a meaningful entity in the real world, in other words its validity. Just as with low mood or anxiety, whilst the experiences and distress are very real, the explanation – that there is an illness called 'schizophrenia' causing them—is increasingly contested.

The usual meaning of the term 'diagnosis' includes ideas of causation and prognosis as well as categorization: in most of medicine, a diagnosis not only categorizes but also explains, indicating the cause of the problem, what is likely to happen over time and what can be done about it (see Johnstone, 2014 for a fuller discussion). However, as Lucy Johnstone explains elsewhere in this special issue this is not the case for mental health 'diagnoses,' which rather than being explanations, are simply ways of categorizing experiences based on what people tell clinicians. It makes no more sense to say that someone hears voices because they 'have schizophrenia' than it would do to say someone has a cough because they 'have cough disorder' (Robinson, quoted in Shariatmadari, 2015). Although some scholarly writing (including DSM-IV [APA, 1994], as noted above) acknowledges this, much does not and it is rarely acknowledged in public information materials (see e.g. APA, n.d.).

Turning to 'prognosis,' outcome is very variable (Kinderman, Read, Moncrieff & Bentall, 2013) and there is also very little evidence that diagnoses are useful in guiding treatment (Moncrieff, 2013).

**The idea of schizophrenia may be doing more harm than good**

Our argument thus far can be summarized as: schizophrenia is essentially an idea. The view that experiences such as hearing voices are symptoms of an underlying illness is only one way of understanding them, and one that is highly contested. There are problems with both the reliability and validity of the diagnosis.

So the question arises: if the idea of schizophrenia is only one possible way of conceptualizing the phenomena in question, is it—and by extension the whole idea of ‘mental illness’—a helpful or useful idea?

The idea of mental illness certainly has some advantages: it gives us a way of talking about difficult things and a framework for offering help, as well as time off work with sick pay or benefits if needed and access to services. It provides a shorthand for people involved in planning services or efforts at prevention. Some of those personally affected welcome a diagnosis because it implies that they are not alone in what they are experiencing (e.g. Falk 2010, quoted in Jones, Lobban & Cooke, 2010, p. 32). Others are concerned that unless they are seen as ‘ill,’ people will blame them or their family for their predicament. This has been called the ‘blame or brain’ dilemma (Boyle, 2013). In summary, the idea of mental illness fulfills—within our current culture and social structures—three vital functions, namely access to validation, income, and support. Those critiquing diagnosis and suggesting alternatives need to bear this in mind and ensure that our critiques do not - particularly in the current *Zeitgeist* of ‘austerity’ and cuts to services—lead to unintended consequences, for example being used as an excuse to reduce vital support.

In other ways, thinking in terms of illness can be unhelpful and many have argued that overall, the idea of mental illness may do more harm than good (e.g. Cooke, 2008; Hickey, 2015; Johnstone, 2014; Kinderman, 2014). People can feel labeled as ‘mental patients,’ disempowered, and sometimes even excluded from

mainstream society (Horn, Johnstone, & Brooke, 2007). A recent review of the experience of 'stigma' (Young Minds, 2010) found that for many people, being seen as mentally ill causes more distress than their original problems. Evidence suggests that people seen as mentally ill are often avoided, treated harshly, and subject to discrimination (Cooke, 2008; Cooke & Harper, 2012; Read, Haslam, Sayce & Davies, 2006) Social Exclusion Unit, 2004). For example, although having a job can be very important in people's recovery, employers are less likely to offer work to someone if they know that they have a psychiatric diagnosis (Mehta & Farina, 1997). Reviews of the available evidence suggest that viewing distress as 'an illness like any other' can actually increase prejudice and discrimination (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Read, Haslam, Sayce, & Davies, 2006). For example, in one study, participants who were told that another person (actually a researcher) had a mental illness opted to give them more electric shocks than if the person's problems were described in more everyday language (Mehta & Farina, 1997). The shocks were fake, but the participants were only told that afterwards. These authors suggest that presenting problems as an 'illness' has the effect of making them seem mysterious and unpredictable, and the people experiencing the problems as 'almost another species.'

Schizophrenia is arguably the archetypal 'mental illness' (Cooke, 2008) and its implications may be even more damaging than is the case with other diagnoses. The usual stereotype can perhaps be summed up as: 'Someone who has psychotic experiences is different from normal people, because his brain (note that the stereotype includes the presumed gender of the individual) is damaged or different, probably because of his genes. He is 'a schizophrenic,' who is not understandable, is dangerous, has no legitimate voice and requires control through drugs which target

the underlying brain disorder.' This stereotype is reflected in, and appears to be maintained by media coverage (e.g. Parry & Moyes, 2013). It is important to remember that those affected by this stereotype include those who are themselves diagnosed with schizophrenia. Some readers may have seen the documentary 'Stranger on the Bridge,' (Forsdyke, 2015) made by Jonny Benjamin, who considered suicide after being diagnosed with schizophrenia. Interviewed by a journalist, he explained "All I knew was what I read in the papers, that people with schizophrenia are violent and incapable of recovery" (O'Hara, 2013).

Whilst some have argued that efforts need to be directed at 'rehabilitating' the concept of schizophrenia in the public mind, perhaps by 'reclaiming' it (as has happened with other originally stigmatizing terms such as 'queer'), others have argued that the social meaning of the concept is so ingrained that such attempts are doomed to failure (Cooke & Harper, 2013; Corrigan & Watson, 2004; Hammersley & McLaughlin, n.d.).

Receiving a diagnosis can also have other negative psychological effects on the person, for example leading to feelings of hopelessness and decreased confidence. It can give the message that people can do little to overcome their problems except to 'keep taking the tablets.' It can divert attention from the personal meaning of the experiences for the person, together with any positive aspects (Herman, 1997).

These disadvantages are illustrated by the following quotes by people who have been given diagnoses of schizophrenia or other 'psychoses':

I was told I had a disease ...I was beginning to undergo that radically dehumanizing and devaluing transformation...from being Pat Deegan to being 'a schizophrenic.

(Deegan, 1993, p. 7)

Being given a diagnosis is like a kick in the teeth. They're not saying that there's something wrong with your liver, but that something is wrong with you.

(Anon, in Jones, Lobban & Cooke, 2010, p. 65)

For a number of years, I accepted the medical model as a framework of understanding... But I gradually came to appreciate drawbacks to the framework. My reading suggested the model might not stand up scientifically. The emphasis on distress as illness not only encouraged a resort to exclusively physical treatments (drugs, ECT) but pushed to one side any consideration of the content and meaning of my crisis episodes. Thinking of myself as having a chronic and incurable illness robbed me of power and agency and confined me within an essentially negative category. By the time I was entering my second decade of service use, the medical model, which I had initially found reassuring, seemed increasingly unsatisfactory, without the capacity to encompass the complexity of my interior or exterior life and give it positive value. As a result, I began to actively explore frameworks that better met my needs.

(Campbell, 2010, p. 22)

“Once past the 'relief response' on learning a name for the distress - the label itself does not alleviate the pain. It does not help the professional or the individual to understand what is happening or what would assist the individual. It stops the individual from owning the experience and finding his/her own language and interpretation. ... the labelled people are seen as

inferior or less competent.... People become dependent and helpless with the treatments and labels.” (Pembroke, 2012, p. 32)

It therefore appears clear that the idea of schizophrenia can have negative effects on those diagnosed. It has also arguably led to professional myopia regarding the events and circumstances of people’s lives that may, for many, be the major reason that their difficulties have developed (Midlands Psychology Group, 2012), diverting attention from underlying social and emotional problems that could otherwise be addressed in a restorative way, for example the aftermath of adversities like poverty, discrimination, childhood abuse or assault (Campbell, 2010). The way that diagnoses appear to summarize the nature and causes of someone’s experience can prevent workers from asking about, and helping the person to deal with the events and emotions that may in reality underlie their problems. The idea of schizophrenia can lead to misplaced certainty, where assumptions about cause and effect are unquestioned and a particular view and particular interventions are imposed on the service user, by force if necessary. It can also divert our focus from efforts at prevention which could arguably make a far bigger difference overall to rates of psychosis (Boyle, 2004). As our colleague John Read has put it “Why do we neglect prevention? The best way of reducing rates of psychosis would be to reduce childhood adversity” (Read, 2014). As the saying goes in public health circles, perhaps mental health services are often ‘trying to mop the floor while the water is still running.’

### **So why is the idea of schizophrenia still so engrained and popular?**

As outlined above, there is increasing acceptance both that ‘psychotic’ experiences are a relatively normal and common phenomenon and that there are significant problems with the reliability, validity and utility of the diagnosis of

schizophrenia. Nevertheless, the idea of schizophrenia remains a very popular one both in the scientific literature and in the popular imagination. Most lay people are unaware that there might be any other explanation for the phenomena in question. We have been struck by the surprise with which journalists and others react to the news that there is no blood test for schizophrenia, for example. So why might this be? What factors might be contributing to the ongoing popularity of schizophrenia as an idea?

Part of the explanation might be the ‘clinician’s illusion.’ This is a form of ‘Berkson’s Bias’ (Berkson, 1950; Maric et al., 2004), namely the tendency to conclude that two things are related when in fact, they both independently affect the phenomenon in question. In this case, the relevant phenomenon is the likelihood that someone will be a current user of mental health services. Many people sometimes experience one or more of the following: finding it hard to look after themselves, feeling desperate, confused or disoriented, hearing voices, and/or thinking suspicious or paranoid thoughts. Contrary to what clinicians have traditionally believed, there is evidence that these experiences are often unrelated to each other (Vázquez-Barquero, Lastra, Cuesta Nuñez, Herrera Castanedo & Dunn, 1996). Those who experience only one or two of these problems are unlikely to seek help from services. By contrast, those who experience several of them, repeatedly and to a severe degree may well need significant help over a long period, come into contact with many clinicians, and receive a schizophrenia diagnosis (Cohen & Cohen, 1984; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007; Ronald et al., 2014). This naturally contributes to a possible impression on the part of clinicians that people who have one of these experiences (for example hearing voices) also tend to have some of the others, to be very distressed, and to have ongoing problems—i.e. to fit the common conception of ‘schizophrenia.’

Another possible contributing factor is the undeniable vested interests at stake. Much of the mental health industry, both in terms of clinical services, their suppliers (e.g., the pharmaceutical companies), and research is predicated on the idea of 'mental illness,' diagnosed by experts and treated with the industry's products. Professional groups and pharmaceutical companies both profit hugely from the idea of schizophrenia (Whitaker & Cosgrove, 2015). The public and journalists naturally rely on the mental health industry for their information, and indeed much public information about 'schizophrenia' is provided or sponsored by pharmaceutical companies, medical organizations or pressure groups. Typical statements include "schizophrenia is a devastating brain disorder..." (National Alliance for the Mentally Ill, n.d.) or "schizophrenia is a chronic brain disorder" (APA, 2015) or "schizophrenia is categorized as a brain disease, not a psychological disorder" (University of Maryland Medical Center, n.d.).

The processes involved are complex, both in academia and in the popular imagination. A fuller examination is beyond the scope of this paper. The interested reader is pointed to work by Mary Boyle (e.g. Boyle, 2002), Diana Rose (e.g. Rose, 2008) and David Pilgrim (e.g. Pilgrim, 2013) among others..

### **Signs of Change?**

The BPS (2014) Understanding psychosis and schizophrenia report generated considerable media coverage, links to some of which (e.g. Allan, 2014; BBC, 2014a, 2014b; Luhrmann, 2015) can be found on the report's webpage, [www.understandingpsychosis.net](http://www.understandingpsychosis.net). Most was extremely positive, although as expected, there were also some trenchant comments from those advocating a more traditional, medicalized understanding of schizophrenia. In the UK, the coordinating editor (AC) was interviewed on the main national radio news program, BBC Radio



4's Today (BBC, 2014b) and the same network also covered the launch in its mental health slot 'All in the Mind. (BBC, 2014a). ' In the print media, the daily broadsheet The Guardian ran two major comment pieces (Allan, 2014; Freeman & Freeman, 2014).

In the US, the New York Times reported favorably on the BPS report (Luhmann, 2015) with an article entitled 'Redefining Mental Illness' which provoked Jeffrey Lieberman, former President of the APA, to don his white coat and post a personal blog entitled 'What Does the New York Times Have Against Psychiatry?' (Lieberman, 2015). In the blog he criticized not only the New York Times article but also the original BPS report (we cover this sub-plot elsewhere in this special edition).

### **Recent developments in the UK**

There are some indications that policy in UK mental health organizations is responding to the increasing scientific concern about the problems with psychiatric diagnosis in general and 'psychotic' diagnoses in particular. Recent high-profile reports (e.g. Rethink/ The Schizophrenia Commission, 2012) have recommended caution. Some have called for the complete abandonment of diagnosis (e.g. British Psychological Society, 2011; British Psychological Society Division of Clinical Psychology, 2013).

One example was the report of the 'Schizophrenia Commission' in 2012 (Rethink / The Schizophrenia Commission, 2012). The Commission was set up by a relatively traditional UK mental health charity, Rethink Mental Illness. The Commission had a mainstream, high-profile membership and was chaired by eminent psychiatrist Professor Sir Robin Murray. Perhaps surprisingly in view of this, and despite its name, the Commission's concluding recommendations included "extreme caution in making a diagnosis of schizophrenia" (p. 7). The reason given was that "it

can generate stigma and unwarranted pessimism” (p. 7). In a recent article called ‘The End of Mental Illness Thinking?’ the current Chair of the BPS DCP, Richard Pemberton (Pemberton & Wainwright, 2014), suggested that

The impetus for a complete overhaul of existing thinking comes from the manifestly poor performance of mental health services in which those with serious mental health problems have reduced life expectancy. It advocates using the advances in our understanding of the psychological, social and physical mechanisms that underpin psychological wellbeing and mental distress, and rejecting the disease model of mental distress as part of an outdated paradigm.” (p. 216)

### **Alternatives to the Schizophrenia Diagnosis**

The issue of possible alternatives to diagnosis, both in general and in case of ‘schizophrenia’ in particular is a complex one that has been explored elsewhere in this special issue, for example by Lucy Johnstone and in our own second paper. It was also the subject of the ‘Global Summit on Diagnostic Alternatives (see e.g. Raskin, 2014) and is the focus of ongoing work within the British Psychological Society Division of Clinical Psychology (e.g. Cromby, 2007; BPS Division of Clinical Psychology, 2014) which has established a ‘Beyond Psychiatric Diagnosis’ committee (BPS Division of Clinical Psychology, 2014). Any alternatives need to address the different functions currently performed (albeit imperfectly) by diagnosis, for example naming, explaining and classifying. Briefly, our own suggestions for the former would take as a starting point a phenomenological approach: a description of the person’s own experience, wherever possible in their own words, for example ‘hearing voices’, without imposing a particular interpretation (see e.g. Kinderman,

Moncrieff & Bentall, 2013). This is the approach adopted by the Hearing Voices Network (see <http://www.hearing-voices.org/>) and by an important new textbook of what has often (mistakenly in our view: see Kinderman, 2016) been called ‘abnormal psychology’ (Harper, Cromby & Reavey, 2013). In terms of explanation, such self-descriptions can be extended by means of a collaboratively developed psychosocial formulation as outlined above. The third function, classification, is arguably a political rather than a strictly clinical one: within insurance-based healthcare systems like that in the US, categories are needed to determine decisions about allocation of resources. They are less necessary within socialized healthcare systems like the one in the UK, where clinicians are able to allocate resources based on individual clinical need.

We would like to leave the last word to someone who has been personally affected by issues raised here. The first author’s departmental blog site ‘Discursive of Tunbridge Wells’ (<https://blogs.canterbury.ac.uk/discursive/>) carries pieces written by service users. Reflecting on her reaction to the widespread debate about diagnosis and the idea of mental illness provoked by the publication of DSM 5, one contributor wrote:

“My family has been shamed and defamed by psychiatric diagnosis. Our lives, historical and present, are forever affected by it. We have felt different. We have felt defective and unacceptable. We felt that our genes were inadequate and shouldn't be reproduced. We felt that our diagnoses had to be hidden because others might think us dangerous or unpredictable. At times, we felt so 'other' that we had to hide our experiences even from one another. We lived

with secrets and silence that reached into every corner of our lives.” (Thomas, 2013)

The author continues:

If psychologists are right that the primary causes of mental illness are psychosocial rather than biological, my family narrative can be re-written. We can emerge from our closets of shame and take our rightful place on the continuum of acceptable human experience."

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