

# Service user perspectives on the impact of a mental illness diagnosis

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**SUMMARY.** **Aim** – to provide a conceptual and practical analysis of the impacts of mental health diagnoses on consumers and to consider how service users might contribute to the new psychiatric classifications currently being drawn up. **Methods** – A search was carried out revealing a very sparse literature on this topic. Consultations with service users were conducted and the views of experts sought. **Results** – Diagnosis is important as it marks the formal status of psychiatric patient being conferred. Consumers react differently, and often, negatively to this. Stigma can follow from a diagnosis. The process of giving a diagnosis can range from one of negotiation and taking the person's strengths into account to the blunt allocation of an unwanted label. Consumers can be reduced to their diagnosis so it becomes their whole personhood and this can have an effect on their sense of self. However, consumers are not passive victims and have their own strategies for dealing with these issues. **Conclusion** – Consumers can use these experiences to make contributions to the new diagnostic classification systems and to future research.

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**KEY WORDS:** psychiatric diagnosis, consumer views, new classification systems, consumer involvement.

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## INTRODUCTION

This paper will discuss a series of key issues relating to psychiatric diagnoses (and their implications) which are of importance when seen from the perspective of service users/consumers. Although people in these groups are the primary intended beneficiaries of treatment and care, relatively few scientific reports represent such views directly. This point of view (Entwistle *et al.*, 1998) has been taken into account in relation to particular treatments (Castle *et al.*, 2002; Rose *et al.*, 2005); needs for care (Beeforth & Wood 2001; Leese *et al.*, 1998); types of psychiatric services (Dickey & Wagenaar, 1994; Lester *et al.*, 2003; O'Toole *et al.*, 2004; Okin *et al.*, 1983; Rose, 2001; Shepherd *et al.*, 1995); employment

(Dalgin & Gilbride, 2003), but less often on diagnosis and classification (Sartorius, 1988; Tylee, 1999; Wasow, 1983). A literature search on Psychinfo, Medline and Embase using the keywords 'psychiatry', 'diagnosis' and 'consumer' retrieved no such articles, revealing that the literature is sparse if not non-existent. We were able to identify a small qualitative study on the perspectives of people with a diagnosis of borderline personality disorder on the label they had been assigned (Horn *et al.*, 2007). Much of this paper is therefore based on consultations with other service users made by the service user author of this paper (DR). Other literature was gathered from experts in the field.

Diagnosis is important to service users/consumers. It marks the point when the formal status of psychiatric patient is conferred. We therefore need to know how this affects the recipients and their various reactions to it as well as to what follows from it in terms of treatment and services. There is no reason to suppose that the reactions of service users are homogenous and we will detail different responses to the allocation of diagnoses. This may also vary with specific diagnoses themselves, for example, in terms of severity.

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### A note on terminology

There is no current consensus on relevant terminology, and the terms 'service user', 'consumer', 'client', 'survivor' and 'person with mental illness' are commonly used in the relevant literature, while 'patient' is still common in many clinical contexts. This paper will use 'service user/consumer' which is, while an unsatisfactory hybrid, we hope at least clear to the reader (Rose *et al.*, 2002; 2006; Rose & Lucas, 2006; Rose, 2001).

### How acceptable are diagnoses to service users/consumers?

There is very little in the literature that considers diagnoses from the point of view of service users/consumers.

### RECEIVING A NEGATIVE LABEL VERSUS NAMING A PERSONAL PROBLEM

We know from anthropological studies that giving something fearful and chaotic a name can render it more acceptable (Douglas, 2002). Receiving a diagnosis can be understood in this way as a naming of something fearful and previously without meaning, thus 'containing' the process. Horn *et al.* found that some of her participants expressed relief that they had at last been given a name for something previously not understood (Horn *et al.*, 2007).

On the other hand, the diagnosis can also be seen as a pernicious label. Some of Horn's participants felt that the diagnostic process demeaned them and undermined their integrity. They felt stigmatised by it. Interestingly, sometimes the same person expressed both of these positions. Related to this, both professionals and service users/consumers may come to see the diagnostic classification as a 'master status'. Instead of the diagnosis being just one feature of the person's self it becomes the defining feature, their core identity. In effect, the diagnosis reduces the person to an instance of a category, thus reifying them. Mental health professionals need to be particularly careful here as if they do not help the client to retain their complex personality then professionals themselves are contributing to stigma and discrimination.

The two reactions may be different for different diagnoses. For example, depression may be a more acceptable diagnosis than schizophrenia, or even personality disorder (Crisp, 2004). However, in some cultures depression may attract just as much stigma as other diagnoses.

Further, it needs to be appreciated that the process of allocation of a diagnosis does not take place in a relationship of equality. Psychiatrists have much more power than their clients – both actual and discursive – and the extent to which this power is apparent in the diagnostic process may affect the service user / consumer's reaction to it.

### DENIAL AND REJECTION

Upon being given a diagnosis, some service users/consumers simply deny it. This is often because of the social stigma attached to psychiatric diagnoses. Service users/consumers may feel that accepting a diagnosis is just too much to bear and so may bury the very idea that such a label has been attached to them. Rejection of a diagnosis is a stronger form of denial. The diagnosis may be seen as unwelcome, even as an affront. Rejection of the diagnosis then may lead to rejection of the psychiatric profession and unwillingness to accept suggested treatment. Once again, there may be differences between different diagnoses with people given the more serious ones most likely to reject them. People with mental health problems are part of the society in which they live and so it is unsurprising that they share in societal beliefs and feelings. In this context, such rejection can be seen as realistic.

### Service users/consumers experience of being (re)diagnosed

It is common for service users/consumers to be given one (or several) diagnoses at one point in time and then for this to be changed at another point in time. For example, the average time from onset to a diagnosis of bipolar disorder is over ten years (Berk *et al.*, 2007). Prior to this, service users/consumers will most often receive diagnoses of either uni-polar depression or personality disorder (or both). Once again, this can be a relief that the problem is finally clearly understood especially when the new diagnosis is a better 'match' to the service user's subjective experience. However, it is also possible that the service user will be very confused by these multiple and changing diagnoses. In a study of service users' perceptions of the success or otherwise of user involvement, one person said:

"I find diagnosis a bit iffy. As soon as you get used to one they change it."

Rose *et al.* (in press)

## INFORMATION GIVING

Read *et al.* (2006), in a review article, estimate that the percentage of people with schizophrenia who are informed about their diagnosis ranges from 7 to 34. Magliano *et al.* (2008) in a participatory study with people with schizophrenia in Italy found that 30% had been informed of their diagnosis. However, 90% said they should be informed about their diagnosis. This information gap indicates that psychiatrists are underestimating the desires of service users to know about their own condition and about how their doctor conceptualises this condition. This raises the question of how a diagnosis *should* be communicated. One important dimension is whether users/consumers consider the diagnostic process to be one of simple allocation of a label or whether the process is seen as one of negotiation. One study found that when the process was considered as one of negotiation, then the person was more satisfied with their care overall (Rose, 2001). Indeed although these issues have been considered in detail in relation to treatment for forms of cancer (Cox *et al.*, 2006a; Fallowfield & Jenkins, 2004; 2006), they have been so far largely ignored in relation to mental disorders except for Alzheimer's disease (Bamford *et al.*, 2004). Nevertheless, Mezzich (2007), then President of the World Psychiatric Association, advocates very strongly a person-centred and holistic approach which focuses on a person's strengths as much as their disabilities. This is consistent with our recommendations below. It might also be thought that the 'recovery approach' would adopt a different conceptualisation of how to give diagnoses in a respectful way. However, a review paper by Slade *et al.* (2008) does not mention diagnosis at all so we are left wondering whether this approach does indeed do away with diagnostic labels altogether or whether some other strategy is being suggested.

## FURTHER ADVANTAGES AND DISADVANTAGES OF RECEIVING A DIAGNOSIS

A series of positive consequences can follow the acceptance, or at least the partial or provisional acceptance, of a diagnosis by a person with mental distress. The person can access information about that condition, for example its features, associations, treatment and prognosis, and test how far this information matches his or her own experience. The primary diagnosis may also bring relief from worry that the problem was some other condition. A clear diagnosis may allow a person to gain access to self-help groups of people with the condition,

and to find there mutual support, for example on how to self-manage the disorder (Mueser *et al.*, 2006), how to self-assess progress (Salyers *et al.*, 2007), or on how to cope with impairments in everyday life that are consequent upon the condition (Mueser & Gingerich, 2005) and self-directed rehabilitation and recovery.

One of the disadvantages of receiving a diagnosis is the commonly assumed association of mental illness with violence (Thornicroft, 2006). However, this association may be reducing in the public mind in relation to common mental disorders, and may be strengthening in relation to diagnoses such as paranoid schizophrenia. Such a diagnosis might be devastating for a person. Interestingly, Lakoff (2006) found that, when patients presented with psychotic symptoms, psychiatrists in Argentina always began with a diagnosis of bipolar disorder as they thought this less stigmatising than a diagnosis of schizophrenia.

A further set of concerns revolves around implications for treatability/untreatability, the belief that the course of the illness will be chronic and the worry, often reinforced by doctors, that there is a strong likelihood of recurrence after a first episode (Repper & Perkins, 2003). Once again, such concerns are more likely to be in place for a particular range of mental health problems and such concerns are not always assuaged by mental health professionals.

There are further worries about the loss of human rights, for example, through incapacity determinations and compulsory treatments (Amnesty International, 2000). This is particularly the case for coercive measures such as seclusion and control and restraint in some countries, mechanical and pharmacological restraints in others and the use of 'cage beds' in some Eastern European countries (Bartlett *et al.*, 2006).

Finally, service users/consumers often receive poor care for physical ailments. 'Diagnostic overshadowing' means that physical problems are seen through the lens of the psychiatric diagnosis leading to under-investigation and under-treatment (Cochlan *et al.*, 2001; Disability Rights Commission, 2006; Druss, 2000). This can lead to higher mortality rates from physical disorders for people with concurrent physical disorders.

## MYTHS ABOUT MENTAL ILLNESS – PUBLIC REACTIONS TO DIAGNOSIS

Within the public domain there is both widespread ignorance and misinformation about mental health problems. A series of popular 'myths' are still commonplace (Hegner, 2000; Jones & Hayward, 2004; Social Exclusion Unit, 2004), for example the following:

- schizophrenia means a split personality
- all ‘schizophrenics’ are violent and dangerous
- people with serious mental illness are completely disabled
- schizophrenia means you can never do anything with your life
- schizophrenia represents a form of creative ‘inner journey’
- they’re lazy and not trying
- it’s all the fault of the genes
- they can’t work
- they are incapable of making their own decisions
- there’s no hope for people with mental illnesses
- mental illnesses cannot affect me
- mental illness is the same as mental retardation
- once people develop mental illnesses, they will never recover
- mental illnesses are brought on by a weakness of character
- psychiatric disorders are not true medical illnesses like diabetes
- mental illness is the result of bad parenting
- depression results from a personality weakness or character flaw, and people who are depressed could just snap out of it if they tried hard enough
- depression is a normal part of the aging process
- if you have a mental illness, you can will it away, and being treated for a psychiatric disorder means you have in some way ‘failed’ or are weak

Further, are low levels of accurate information about people with a diagnosis of mental illnesses consistent between different countries and cultures? Information here is sparse (Thornicroft, 2006), but several points are clear. First, there is no known country, society or culture in which people with a diagnosis are considered to have the same value and to be as acceptable as people who do not have mental illness (Thornicroft *et al.*, 2009). Second, the quality of information that we have is relatively poor, with very few comparative studies between countries or over time. We do, however, need to distinguish between sparse information, and wrong or misinformation (myths). Third, there do seem to be clear links between popular understandings of the meaning of a diagnosis of mental illness, people’s willingness to seek help, and whether they feel able to disclose their problems (Littlewood, 1998). The core experiences of shame (to oneself and one’s family) and blame (from others) are common everywhere stigma has been studied, but to differing extents. Where comparisons with other conditions, such as visual impairment, have been made, people with a diagnosis of

mental illnesses are more, or far more, stigmatised (Lai *et al.*, 2001; Lee *et al.*, 2005), and mental illnesses have been referred to as the ‘ultimate stigma’ (Falk, 2001). Finally, rejection and avoidance of people with a diagnosis of mental illness appear to be universal phenomena.

## SELF-STIGMATISATION FOLLOWING DIAGNOSIS

A very important consequence of diagnosis is that some people with mental illness themselves come to see their diagnosis as the ‘master status’ discussed above. This is encouraged by the common use in medical and research writings of terms such as ‘schizophrenics’, or ‘depressives’, whereas it would be unacceptable to refer to people with heart disease as ‘cardiacs’. This progression from seeing oneself as having a particular condition (along with many other characteristics and attributes), to being essentially identified by the disorder is a crucial step as these labels confer a lower social value on people to whom they stick (Biernat & Dovidio, 2000; Dovidio *et al.*, 2000; Smart & Wegner, 2000; 1999), both in that person’s own eyes, and in the estimation of others. In short, the social identity of people with mental illness can be influenced by the person’s own sense of what it means to have a mental illness, by the expected discriminatory reactions of others, and by the actual reactions of others. Combinations of these factors can lead to material poverty (Estroff, 1981), social marginalisation (Dear & Wolch, 1992), and reduced social participation (Social Exclusion Unit, 2004).

People with a diagnosis of mental illness may not be willing to disclose it. This is often seen as an aspect of self-stigmatisation. However, not all people with a diagnosis passively accept it as we have seen. Non-disclosure need not imply passivity but may be an active choice to avoid discrimination and preserve one’s own integrity.

The INDIGO (International Study of Discrimination and Stigma Outcomes) Study in 28 countries across the world conducted face-to-face interviews that were completed with 736 people with a clinical diagnosis of schizophrenia. The main purpose of the study was to assess anticipated and experienced discrimination. Several questions related to the name of the condition. In reply to the question ‘Do you know what diagnosis your doctor has made?’ 83% answered yes. To the question ‘Do you agree with the diagnosis?’; 72% agreed, 17% disagreed and 10% were unsure. For the question ‘How much has it been an advantage or disadvantage for you

to have the specific diagnosis of schizophrenia?' 54% reported disadvantage, 26% advantage (e.g. in directing them to information on the condition, to a self-help group, or to assistance with housing or welfare benefits), while 18% reported no difference. Most people given or offered this diagnosis therefore saw it, on balance, as a negative rather than a positive attribute (Thornicroft *et al.*, 2009).

## AETIOLOGY

A diagnostic consultation may also include explanation of the causes of the condition. Here there are discrepancies between clinicians and the public and consumers. Leading health organisations, such as the World Psychiatric Association, (Sartorius, 2000) describe a belief that schizophrenia, for example, is a 'debilitating disease' as sophisticated and knowledgeable. It thus has the status of 'fact'. The public, on the other hand, attribute mental health problems to psychosocial and other life factors (Angermeyer *et al.*, 2005). In their review of anti-stigma campaigns which adopt a 'mental illness is an illness like any other' approach, Read *et al.* (2006) argue that this approach consolidates stigma because disease of the brain invokes images of being out of control and unpredictable. This does not mean that the public is not on occasion frankly wrong about mental health problems and we discussed this above.

This gap between clinician's views and public and patient views has implications for the diagnostic process. Focusing too much on a biomedical aetiology may increase self-stigmatisation for some people. Clinicians need to be alert to the consequences of the information they impart for the individual concerned. After all, the biomedical approach remains unproven.

## NEW TECHNOLOGY

The internet has radically changed communication with websites, chat rooms and email threads. These exist on a huge range of topics including mental health topics. Read (2008) examined 50 websites on the topic of schizophrenia. More than half were funded by pharmaceutical companies. These websites were more likely to adopt a biochemical view of schizophrenia, likely to promote the use of medication and associate coming off medication with relapse and dangerousness. The internet has entered into public dialogue and has its own effects on stigma, at least towards those with more severe diagnoses.

## CHANGING DIAGNOSTIC TERMS

In a unique move aimed to reduce social rejection, the name for schizophrenia has been changed in Japan. Following a decade of pressure from family member groups, including Zenkaren, the name for this condition was changed from *seishin bunretsu byo* (split-mind disorder) to *togo shiccho sho* (integrative disorder) (Desapriya & Nobutada, 2002; Takizawa, 1993). When the previous term was used, only 20% of people with this condition were told the diagnosis by their doctors (Goto, 2003; Kim & Berrios, 2001; Mino *et al.*, 2001). There are indications from service users/consumers and family members that the new term is seen as less stigmatising and is more often discussed openly. This is consistent with work in Germany suggesting that giving the label 'schizophrenia' has a significant and negative effect on public perceptions (Angermeyer & Matschinger, 2005).

However, changing names can be very complex both politically and for practice. Salvador-Corulla & Bertelli (2008) describe the intricate processes that were in play when the shift was made from 'mental retardation' to 'intellectual disability'. There were economic, policy and political implications as well as differences between stakeholder groups on whether this new terminology should be used. It is unlikely that changing terminology for different mental health conditions would be any less complex and challenging.

## LOGICAL ONTOLOGY – LANGUAGE-INDEPENDENT MEANINGS

Finally, there have been arguments that diagnostic categories should be based on language-independent logic. Schulz *et al.* (2008) point out that much terminology concerning disease classification, processes and interventions are ambiguous semantically. They propose a logical ontological system – SNOMED-CT – to help resolve this problem. In this system, logical elements are conjoined to specify a disease, process or intervention. This might seem attractive in psychiatry as it would remove the 'subjectivity' of the clinician, a subjectivity that has often been criticised. However, Schulz *et al.* (2008) give examples only from physical medicine where organs and procedures can be easily specified and combined. In fact, when the revision of DSM-IV was first mooted it was hoped that biomarkers could be identified in precisely this way. This is not yet possible in practice although for many clinical academics it is still the goal. Consumers tend to reject this. What is desired is a negotiated and meaningful diagnosis

in which they have some power. We would argue that a 'language independent' classification system in mental health is a long way off and carries the possibility that clinicians will no longer have to have conversations with patients. However, it can be argued that any name change in medicine should include this perspective.

## **SERVICE USER PARTICIPATION IN NEW DIAGNOSTIC AND CLASSIFICATION SYSTEMS**

DSM IV and ICD10 are in the process of being updated and so this is an opportunity for the service user voice to enter these deliberations. In writing this review it has become clear that many of the issues we raise have little formal scientific evidence base. We have therefore identified the following key recommendations on current action and on how to strengthen the evidence base on the public health implications of diagnostic and classificatory systems, and their implementation.

Concerning what can be done given current knowledge, we recommend that the new systems of classification of mental health problems carefully consider the following issues:

- The new classifications should not be 'totalising'. In other words, mental health professionals should not assume that a diagnosis of mental disorder should be used as the essential defining feature of a person (a so called 'master identity'). The debate about dimensions rather than categories is relevant here as categorical classification suggests that the person with the diagnosis is categorically different to 'us'. A dimensional approach would allow the service user to see their problems as part of a continuum that includes the whole society.
- It would be helpful if clinicians were given guidance on assisting service users/ consumers to fully recognise their assets and the positive aspects of their lives when a diagnostic consultation takes place. Typically, the focus is only on deficits – cognitive, social and emotional – whereas no-one is a 'bundle of deficits'. This should be to the forefront of the clinician's practice.
- Any new diagnostic manual should contain a chapter explaining to clinicians how psychiatric diagnoses, especially those which may be more severely disabling, may have profoundly stigmatising effects. Guidance should be provided on how this knowledge should be woven into any consultation where a diagnosis is given or discussed, along with references to resources, which can assist individuals and families in coping with stigmatising reactions from others. Clinicians should also ensure that they are not themselves stigmatising their patients in giving the diagnosis itself and how it is given.
- Knowledge should not be esoteric. A short user-friendly version of any new diagnostic manual should be prepared so that service users/consumers know what their doctor is talking about. A loose-leaf format would enable the service user to be given the information relevant to the diagnosis they have been assigned.
- Those constructing new classification systems should also listen to consumers who reject the diagnostic classification systems completely. There is an understandable tendency to dismiss such views out of hand but our view is that the conversation is necessary.
- Ethical principles related to the diagnosis of mental disorders should be compiled for inclusion in the front of the classification (e.g., warnings against misuse of the diagnosis, use of person-first language, avoiding the use of diagnoses as names).

For the future, there is a need to undertake research and this research should fully involve service users. Among others, key issues that require further investigation include:

- Whether changing the names and diagnostic terms applied to conditions changes their degree of acceptability to service users/consumers, (Lieberman & First, 2007). For example, the implications of renaming manic depression as bipolar disorder.
- Whether there is a need for a greater understanding by mental health professionals of explanatory models of health and the differences between the paradigms of staff making and giving diagnoses and people receiving these diagnoses (Cox *et al.*, 2006b).
- The effects of different methods of giving/offering diagnoses, the comprehensibility of different rationales for the diagnosis, and how far these are accepted by service users/consumers.
- The implications of involvement of service users/consumers as active participants in a negotiation process and whether this changes the acceptability to service users/consumers of receiving a diagnosis.
- How far receiving a diagnosis is experienced as an empowering or a dis-empowering process by services users/consumers.
- The impact of giving opportunities to engage carers and family members for information sharing at the time of diagnosis and the proper and practical limits of confidentiality.

## CONCLUSIONS

This paper has presented evidence that many people with mental health problems are faced with forms of discrimination that have the effect of promoting social exclusion and that diagnoses can be important elements in these complex processes which appear to be active worldwide. It is not often recognised that mental health professionals themselves can contribute to stigma and discrimination (Lauber *et al.*, 2006; Nordt *et al.*, 2006). Finally, it can be argued that the process of giving a diagnosis of mental illness is a form of ‘unintentional discrimination’ by mental health professionals in that while therapeutically intended, it may lead to harmful consequences for the service user/consumer.

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