East Midlands Psychosis and Complex Mental Health

Special Interest Group:

Position on Psychiatric Diagnosis

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1. Synopsis

Background. The following details the East Midlands Psychosis and Complex Mental Health Special Interest Group's (SPIG) position on psychiatric diagnosis. Psychiatric diagnosis is the dominant framework used to conceptualise distress within mental health services. Diagnosis is embedded within the mental health system and is utilised in relationships with other social institutions, such as with social services and the legal system. Diagnosis claims its dominant place by portraying itself as a specialist form of knowledge with a scientific basis.

Position on Scientific Claims. The SPIG's position is that psychiatric diagnosis does not meet its scientific and expert claims. Therefore, psychiatric diagnosis does not have an unassailable claim on the truth and does not warrant promotion as the dominant form of knowledge and currency within mental health services.

Current Functions. A number of practical functions have been claimed for diagnosis: 1) communication; 2) legitimating distress; 3) treatment. The utility of diagnosis in meeting these functions however is critiqued and alternatives offered within the paper. Critics of diagnosis have also argued that one of the key functions of diagnosis is maintenance of professional dominance.

Negative Effects. The paper highlights a number of negative impacts of psychiatric diagnosis:

1) the privileging of individualistic biological explanations and research, at the expense of contextual understandings and research; 2) an imposition of a western cultural worldview; 3) the creation of a barrier to equitable communication between mental health staff and service users; 4) the exclusion of other forms of knowledge, including undermining the perspective of service users; 5) the hindering of the formation of shared explanations.

Alternatives to Diagnosis: The paper notes initial suggestions for starting to move beyond diagnosis by: 1) focussing on specific experiences and difficulties within a person's life and world. In practice this will create the potential for a greater shared language between staff and service users, and a sounder foundation for research; 2) contextualising and making sense of unusual experiences, which would include treating such experiences as meaningful within a person's life experiences and social-material world; 3) broadening what constitutes knowledge and taking a questioning stance to all forms of knowledge. This would necessitate taking personal experience as a form of knowledge, and increasing the range of explanations entertained for understanding unusual experiences; 4) using contextual measures for administrative tasks. Assessments, referral pathways, discharge letters, and communication

with other social institutions could use criteria based upon a person's difficulties and strengths within their social-material world.

2. Introduction

Psychiatric diagnosis holds a central position within mental health services for understanding distress and unusual experiences, and has become an everyday and often unquestioned part of mental health practice. For example, diagnosis is used routinely as part of the referral and assessment process, and is frequently the basis for explaining to service users, families and wider society the reason for a person's distress. Furthermore it is used to design services, allocate resources, and functions to justify actions taken to address unusual experiences. Psychiatric diagnosis is also central to much mental health research and forms the basis of evidence based practice in the form of National Institute for Clinical Excellence guidelines (e.g. NICE, 2009). Further, psychiatric classification is the foundation of many of the administrative practices within mental health services and its interface with social services and benefits system. The categorisation of a person as 'mentally disordered' means that the legal system will treat a person differently to other citizens (Vassilev & Pilgrim, 2007).

Whilst biomedical models and psychiatric diagnosis dominate mental health practice, the conceptualisation of distress and ideas of what might help is contested between and within professionals, academics, patients, service users and survivors, and amongst the general population. A recent example of resistance to psychiatric knowledge is the Campaign for Abolition of the Schizophrenia Label (CASL), a coalition of interested parties, who state that: "the concept of schizophrenia is unscientific and has outlived any usefulness it may once have claimed" and the "label schizophrenia is extremely damaging to those to whom it is applied."

The current paper questions whether the claims of psychiatric diagnosis to expertise and scientific respectability are justified and therefore whether its central place within the mental health system is merited. Some of the functions and effects of psychiatric diagnosis are then outlined. The paper considers alternatives to using psychiatric diagnosis. The paper has been formulated by the East Midlands SPIG, which comprises Clinical Psychologists working in mental health services across the region, which includes representatives from Nottinghamshire, Derbyshire, Leicestershire, Sheffield and Lincolnshire. The statement

generally refers to the diagnosis of schizophrenia¹, and related classifications, although there is recognition within the group that many of the issues detailed below are applicable to the psychiatric classification system as a whole.

3. How Robust is the Scientific Basis of Psychiatric Diagnosis?

If diagnosis is to claim status as a form of scientific knowledge it may be judged against two basic forms of scientific criteria: reliability (can categories be consistently assigned) and validity (are diagnostic categories meaningful). Psychiatric diagnosis, unlike much of medical diagnosis lacks biological signs. It is therefore reliant on what people say and do, which is open to interpretation. Early research showed that clinicians often disagreed about what psychiatric diagnosis to assign someone (Blashfied, 1973; BPS, 2000). Considerable effort has gone into improving reliability with DSM III and IV and there has been some advancement, however, such improvements are relatively modest and decrease once used in day to day clinical practice (Kirk & Kutchins, 1994; Mojtabi & Nicholson, 1995).

In terms of validity, Boyle (1999; 2002a) notes that the creation of the diagnostic label of schizophrenia should have been based on the existence of a meaningful pattern between different symptoms; however, there is no evidence that such a meaningful pattern was discovered. Statistical analysis highlights that symptoms do not cluster together in the manner predicted by diagnostic frameworks (see BPS, 2000 for overview). The diagnostic system suggests a distinct difference between everyday (normal) experiences and unusual (abnormal) experiences, but research highlights a continuum of experience (see Bentall, 2003). The diagnostic system predicts a clear difference between disorders, yet there is actually extensive overlap between diagnostic categories (BPS, 2000). Overall, research suggests that diagnostic categories do not reflect any real or meaningful patterns.

Additional criteria of the validity and utility of diagnosis are its ability to predict outcome and suggest what treatments might be helpful. However, there is a great variability in the outcome, symptomatically and socially, of people given a diagnosis of "schizophrenia" (BPS, 2000; Ciompi, 1984). Also, research highlights that diagnosis is limited in predicting response to psychiatric drugs and more attention should be paid to specific experiences and difficulties, for example hearing voices, mood and so forth (BPS, 2000; Healy, 2008; Moncrieff, 1997; 2008; Rogers et al. 1998). Boyle (2007) points out that it is not really surprising that a system

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¹ It is acknowledged that whilst the concept of 'psychosis' has certain advantages over schizophrenia (such as a greater application of 'normal' theory and an increased focus on people's experiences), both terms also share a number of flaws (see Johnstone, 2009)

(medical diagnosis) created to study body parts does not work when applied to psychological experience and behaviour, she notes body parts "don't have language or emotions, form beliefs, make relationships, create symbols, search for meaning, or plan for the future" (p 290).

4. Functions of Psychiatric Diagnosis

Psychiatric diagnosis does not meet the scientific criteria it claims. However, a number of functions have been claimed for diagnosis to support its continuation, which can be broadly summarised as:

Communication: Psychiatric diagnosis is currently key to accessing mental health services and the basis of communication with agencies outside of mental health services (benefits system, social services, legal system), as well as used to organise evidence based practice (see section 5.3 for difficulties with basing communication on diagnosis and, section 6.1 and 6.4 for alternatives).

Legitimating Distress: It is stated that for some clients psychiatric diagnosis can help them to feel understood and contained particularly at times of distress. Furthermore, some people within mental health services value having a diagnosis, and the parallel with medical diagnosis and 'illness' can help remove feelings of personal blame (see section 5.4 for problems with using diagnosis to explain distress and, section 6.1 and 6.2 for alternatives).

Treatment: Some medical practitioners believe that diagnosis can help decide what psychiatric medication may help as well as predicting outcome (see section 3 for evidence against this).

Boyle (2007) and Pilgrim (2007) have argued that one of the key functions of psychiatric diagnosis is the maintenance of professional dominance via the enclosure of a 'specialist knowledge' that can only be used by professional experts (see Pilgrim, 2007, for a discussion of the complex network of interest groups maintaining the persistence of diagnosis).

5. The Negative Effects of Psychiatric Diagnosis

5.1 Privileging Biology, Pathologising Individuals and Obscuring Context

Basing the conceptualisation of unusual experiences and distress on the classification system of bodily dysfunction (medical diagnosis) implies that such experiences are driven and underpinned by a physical and individual abnormality. This has led to research focusing on

biological factors at the expense of social and psychological research (Boyle, 2002a). Despite a lack of funding of research into the social context of distress, there is considerable evidence for all forms of distress (including unusual experiences) being shaped by people's social-material worlds (e.g. Bentall & Fernyhough, 2008; Cromby & Harper, 2009; Friedli, 2009; Janssen et al. 2003; Werner, Malaspina & Rabinowitz, 2007; Wicks, Hjern, Gunnell, Lewis & Dalman, 2005).

Within mental health practice, psychiatric diagnosis implies an individual and biological abnormality, which obscures the damaging environments people have experienced and inhibits staff from looking for causes in people's lives, rather than in brains and minds (Boyle, 2002a; 2008). Boyle (2002b, p.9) notes that there is a '...discrepancy between the strength of the belief that "schizophrenia is a brain disease" and the availability of direct supporting evidence'. Boyle highlights that this is despite prominent advocates of such a belief acknowledging the lack of such evidence. Furthermore, diagnosis constructs people and their identity in terms of individual deficits rather than highlighting their strengths - often in the face of difficult circumstances. In essence, people's lives are reduced to a basic classification system which hides the reality of their lives and context.

5.2 Imposing a Western Cultural Worldview

Diagnosis suggests a standardised way of classifying illness and abnormality, however, experiences classified as 'abnormal' in one culture can be viewed differently in another. For example, from the perspective of psychiatric diagnosis the experience of hearing voices ("auditory hallucinations") is seen as a symptom of an illness, yet within some communities hearing voices is considered a spiritual gift (Romme & Escher, 1993). Fernando (2002) has highlighted how psychiatric diagnosis is embedded in the history of western philosophy and ideology, and so enshrines a western worldview². However, the practice of psychiatric diagnosis does not recognise that it is a *cultural practice* and diagnostic categories are culturally embedded. This lack of recognition leads to western culturally formed diagnostic categories being applied universally, despite the fact that such classifications may not be coherent or valid in other cultures (Andary, Stolk & Klimidis, 2003; Fenton, 1999; Kleinman, 1987; Mezzich et al. 1999). Furthermore, the logic of a diagnostic system requires a coherent pattern of symptoms to be identifiable for each diagnostic category. However, the evidence reviewed previously in Section 3 highlights that classifications, such as schizophrenia, lack conceptual coherence and validity even within the culture from which they were derived (e.g. BPS, 2000). Additionally, concepts such as schizophrenia are contested within western

² It should be noted that many psychological concepts share similar difficulties (Owusu-Bempah & Howitt, 2000).

culture. For example the Hearing Voices Network challenges the notion that 'auditory hallucinations' are meaningless symptoms of an illness, and provides the alternative that hearing voices are personally meaningful (see also CASL, and Pilgrim, 2007, for a description of how psychiatric diagnosis has been contested). Overall, psychiatric diagnosis appears to be a problematic way of understanding people who adopt western cultural values, beliefs and practices. Furthermore, people who diverge from a western cultural background³ are even more likely to feel misunderstood, pathologised and their worldview invalidated by the practice of psychiatric diagnosis.

5.3 Barrier to Communication

The specialist and abstract language of psychiatric diagnosis can be one barrier preventing people using services from entering into an equitable conversation with mental health staff. The medical discourse of diagnosis claims an expertise which subordinates the service users' language and explanations of their experiences. Any open communication and negotiation between staff and service users is therefore automatically skewed in the favour of staff, even without taking account of the users' level of distress, legal status under the Mental Health Act, educational background and so forth. The lack of shared language is particularly unfortunate as diagnosis provides little real explanatory value as it is based on tautological reasoning (see Pilgrim, 2000; 2005). It therefore seems unnecessary within mental health services for notions such as "schizophrenia" to be invoked; instead a shared language could be used, such as discussing voices.

5.4 Excluding User Perspectives and Hindering Shared Explanations

The use of claims to specialist knowledge such as psychiatric diagnosis can lead to the perspectives of people with unusual experience being undermined and given little weight (see Borg, Karlsson & Kim, 2009; Deegan, 1990). Furthermore, biogenetic models dismiss unusual experiences as meaningless and so in practice there is little reason for mental health staff to form a shared and collaborative understanding of someone's experiences. Instead professional explanations are imposed with varying degrees of vigour. However, research highlights that unusual beliefs are meaningful and can relate to important themes and goals in a person's life or have an important function for people in difficult circumstances (e.g. Cromby & Harper, 2009; Harper, 2004; Rhodes & Jakes, 2000; Roberts, 1991). Such experiences are often only explicable through an understanding of a person's life history and social world, which is inhibited from exploration by the framework of psychiatric diagnosis. For some

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³ For a general overview of mental health and diversity see Rogers and Pilgrim (2005). For specific discussions on: gender see Busfield (1996); sexuality see Bayer (1987); and social class see Wilkinson and Pickering (2009).

service users being given a diagnosis and told they have an illness can appear to provide an explanation. However this explanation is actually illusory, given the lack of validity of diagnosis and the circular logic on which it is founded. Moreover, there are alternative and more meaningful ways to make sense of people's experiences.

6. Alternatives to Psychiatric Diagnosis

Psychiatric diagnosis has become embedded within multiple systems inside and outside of mental health services and there are a variety of interest groups supporting its continuation (Pilgrim, 2007). Therefore, the issue of moving beyond diagnosis is complex, requiring work at multiple levels and the determination of various groups to move the agenda forward. Psychology has the potential to be one of these groups advancing the agenda, although Psychology has not acted consistently in its approach to diagnosis. The following are modest and initial suggestions for starting to realise an alternative to psychiatric diagnosis.

6.1 Focussing on Specific Experiences and Difficulties

Instead of using diagnostic categories, the accounts people give of their experiences and lives should be the main communicative currency. This might include discussing specific experiences such as suspiciousness, mood, hearing voices (Bentall, 2003), but may also focus on other aspects of a person's life and world. This approach has several advantages. It means a language can be used that is closer to the experiences reported by those experiencing them. This will increase the likelihood of a shared language being used, which would enhance communication and the potential for collaboration and negotiation. Dispensing with diagnosis and replacing it with specific difficulties severs the assumptions brought across from medical diagnosis, and removes one obstacle to rebalancing the currently biological biased biopsychosocial model of unusual experiences (see Read, 2005). Research can also be based around specific experiences and such lines of research appear to be making significant advancement (Bentall, 2007). Furthermore, dispensing with conceptually contested terminology and using a shared language may allow cross-fertilisation of academic specialities in researching distress, such as between Sociology and Psychiatry (Pilgrim & Rogers, 2005).

6.2 Contextualising and Making Sense of Unusual Experiences

There is considerable evidence that experiences such as paranoia, hearing voices and unusual beliefs are not categorically different to everyday experiences (BPS, 2000). Conceptualising unusual experiences on a continuum with everyday experiences can help

staff to have greater empathy, acceptance and understanding of such experiences. Such a contextual understanding can also serve the function of removing unwarranted personal blame. As noted previously, research highlights that unusual experiences are often meaningful; for example underlying themes may reflect thwarted goals in life, confusing or emotionally painful experiences, aversive social circumstances, limited resources and power, or difficult emotions (BPS, 2000; Cromby & Harper, 2009; Harper, 2004; Johnstone, 2007; Mirowsky & Ross, 1983; Morrison, Frame & Larkin, 2003; Rhodes & Jakes, 2000; Roberts, 1991). Supporting someone to make sense of their experiences will require collaboration. sensitivity and respect for the person's perspective. This would involve negotiating a shared meaning of their difficulties and wherever possible a way forward. It would also often entail understanding people's experiences in relation to their social world and life history. Furthermore, it will necessitate sensitivity to the person's cultural background and require staff members to reflect on how their own background (including aspects such as gender, sexuality and class) shapes their own worldview and practice. Pilgrim (2000) notes an understanding of a person's context is more likely to help us understand their needs than the label of "schizophrenia". Such contextualisation and validation of the severity of a person's distress can legitimate their distress as understandable given their life experiences.

6.3 Broadening what Constitutes Knowledge and Taking a Questioning Stance

The perspective and experience of service users has often been sidelined within mental health services (Borg et al. 2009; Deegan, 1990). This has often occurred through mental health professionals claims to expertise, objectivity and 'evidence based practice' (Borg et al. 2009). Such claims legitimate certain forms of knowledge and in doing so diminish other forms (Foucault, 1973/94). A number of critics have argued that, in general, professionals have been too narrow in what constitutes knowledge, and such knowledge has not always been subjected to adequate scrutiny (see Diamond, 2008; Ingleby, 1981; Moloney & Kelly, 2003; Nightingale & Cromby, 1999; Pilgrim, 2007; Rogers & Pilgrim, 2005). The position of this paper is that the stories of service users should be taken as a form of evidence (Read & Reynolds, 1996). The Hearing Voices Network is an example of experientially grounded knowledge that can be shared and of use to others for understanding and coping with voices. The position paper also advocates that a questioning approach should be taken to all forms of knowledge. Morgan (2008, p68.) highlights that whilst "we must begin with the accounts people give of their experiences", lived experience should not be treated "as a foundational given". For professionals, a questioning approach to knowledge requires reflecting on the social forces, power and interest shaping professional knowledge and scrutinising the status of dominant ideas and practice.

6.4 Using Contextual Measures for Administrative Tasks

As noted previously psychiatric diagnosis is often used within a variety of administrative tasks, so to communicate a shared understanding within and between agencies (such as assessments, referral pathways and discharge letters). However the lack of conceptual integrity of terms such as schizophrenia, means the communicative value of such a label is at worst meaningless, at best imprecise and always gives limited information of a person's needs and experiences. Alternatively, referral criteria and communication could be based upon a contextual understanding of a person's world, in combination with information on the specific difficulties experienced and level of distress. For example, a person's resources in their world (or lack of) could be used as a foundation for assessment and referral criteria such as the power-mapping tool by Hagan and Smail (1997). Such a tool can be used qualitatively and quantitatively to map strengths and difficulties in terms of home and family life, social life, material resources and personal resources. Whilst such criteria would be longer than a one word label, they would carry much more information about a person's needs. Furthermore, such a contextual assessment would meet many of the information requirements for social services documentation.

7. Final Comments

This paper has outlined a critique of, and alternative to psychiatric diagnosis. It has noted that diagnosis does not convey meaningful information, that claims to scientific respectability are unfounded and that there are several negative effects with its continued use. The paper has also sketched out realistic and progressive alternatives to psychiatric diagnosis. It should be highlighted that this paper recognises that people have significantly distressing experiences and circumstances and finding an alternative to diagnosis does not undermine these difficulties and experiences, rather it hopes to create more meaningful and personally informed ways of helping and providing support.

This paper is not a rejection of Psychiatry, but a critique of a specific practice that has been used by many professionals including Psychologists, and which has also been criticised from within the psychiatric profession. The East Midlands SPIG is also aware that the practice and concepts of Psychology requires ongoing reflection and critique. This paper is a call for a shared framework and language that can be used by Psychiatry, Psychology, the Social Sciences and people experiencing distress, so that a richer and more nuanced knowledge can be created, and ideas for helping developed and shared.

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