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Changing society's whole approach to psychosis

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Anne Cooke, editor of the British Psychological Society's recent high profile report 'Understanding Psychosis and Schizophrenia' outlines the motivation behind it, its main messages, and the debate it has provoked.

The British Psychological Society's report 'Understanding Psychosis and Schizophrenia: why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help' (Cooke, 2014) has generated extensive media coverage and debate. It is a book-length consensus report outlining in everyday language a psychosocial approach to experiences that are commonly thought of as psychosis. Written by a group of 24 authors including many of the leading psychology researchers in the field, together with people who have themselves experienced psychosis, it aims to provide an accessible overview of the current state of knowledge in language that everyone can understand.

In contrast to many extant public information materials which tend to argue that schizophrenia is a brain disease (e.g. University of Maryland, n.d.), but in line with the views of many contributors to this journal (e.g. Beck et al., 2012) the report outlines a psychosocial approach, arguing that even the most severe distress and the most puzzling behaviour can often be understood psychologically. It also describes psychological and social approaches to helping, exhorting professionals not to insist that service users accept any one particular framework of understanding, for example that their experiences are symptoms of an illness. It has attracted significant attention in the UK and world media. For example its release was covered in the UK by BBC Radio 4's 'Today' programme (BBC, 2014) and in the USA by the New York Times, where it was the subject of an article entitled 'Redefining Mental Illness' (Luhmann, 2015).

The document had its origins back in 1999. A group of NHS and academic clinical psychologists were outraged at the widespread misinformation and atrocious stereotypes that were dominating media coverage at the time, particularly with respect to psychosis, with headlines like *Free to kill - lunatics left to roam streets butcher 90 people a year* (from the now defunct but then very popular *News of the World*) and people with mental health problems referred to as 'walking time bombs' even in broadsheet newspapers (e.g. *The Guardian*, 1999). We felt that our profession had a responsibility to challenge these stereotypes, and that we had something unique to contribute as psychologists. Research into the psychology of psychosis was burgeoning, and many of its findings were challenging not only media stereotypes but also much 'accepted wisdom' within mental health services as well.

For example, research was revealing that 'psychotic' experiences are actually very common. Thousands of people have unusual beliefs or hear voices, but live successful lives and never come into contact with mental health services. Evidence was also accumulating that rather than

being some scary mystery brain disease, psychosis can often be a reaction to the things that happen to us – for example abuse and trauma – and the way we make sense of those events.

We summarised the latest research into one easy-to-read document aimed at service users, journalists, policy makers and the public. We hoped not only to challenge the myths, but also to provide a resource for people who might not have come across all these ideas or research studies before. In particular, believing that ‘information is power’, we hoped that a summary of the various debates and evidence with regard to ‘psychotic’ experiences would be useful to service users. We wanted it to be a resource that people could draw on in their negotiations with professionals who issue advice and sometimes even use coercion on the basis of their claimed expertise. Twenty of the leading clinical psychologists in the field contributed, and in the summer of 2000 the report was published, under the now somewhat anachronistic sounding title of ‘Recent Advances in Understanding Mental Illness and Psychotic Experiences’ (Kinderman & Cooke, 2000). Later, with a grant from the UK Government Department of Health, we produced a set of training materials, *Psychosis Revisited* (Basset, Cooke & Read, 2003), which became a bestseller (Basset, Cooke & Read, 2007; Butt, Brown & Hayward, 2010). In 2010 the DCP published a second public information report, this time about the tendency to experience extreme moods that can lead to a ‘bipolar’ diagnosis, edited by Steven Jones, Fiona Lobban and myself (Jones, Lobban & Cooke, 2010).

In 2012 the DCP asked me to lead a project to produce an updated report on psychosis, summarising the huge progress made over the intervening years in consolidating a consistently psychological approach to understanding and helping with ‘psychotic’ experiences. Most of those who had contributed the first time were keen to be part of this new project too. There were also new contributors, many of them younger researchers who had come to prominence since the first report, for example Tony Morrison and Daniel Freeman. Significantly, and as is now common practice with articles in this journal (e.g. Wykes & Brown, 2015), the document was co-produced with people with personal experience. Around a quarter of the contributors had themselves experienced psychosis, including some of the psychologists.

Our primary target audience is the public and those who help shape public opinion, such as journalists, as well as mental health staff, service users and their families. Available free from www.understandingpsychosis.net, (free hard copies from membertnetworkservices@bps.org.uk) it is written in everyday English rather than professional language, and includes an extensive list of further resources, with web links. Swedish and Spanish versions are also now available.

Its main messages are:

- The problems we think of as ‘psychosis’ – hearing voices, believing things that others find strange, or appearing out of touch with reality – can be understood in the same way as other psychological problems such as anxiety or shyness.
- They are often a reaction to trauma or adversity of some kind which impacts on the way we experience and interpret the world.
- They rarely lead to violence.
- No-one can tell for sure what has caused a particular person’s problems. The only way is to sit down with them and try and work it out. The opportunity to talk things through in this way is vital, but surprisingly rare. Psychological therapy needs to be available to everyone who is distressed by ‘psychotic’ experiences.
- Services should not insist that people see themselves as ill. Some 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.
- We need to invest much more in prevention by attending to inequality and child maltreatment. Concentrating resources only on treating existing problems is like mopping the floor while the tap is still running.

The implications of this analysis for services are significant. For example, whilst medication has a place, the emphasis shifts from ‘waiting for the meds to work’ to helping each person to make sense of their experiences and to find the support that works for them. Perhaps one day the default approach in psychosis services will be a psychological one, with a psychological formulation driving every decision and the content of every conversation. We hope that our document will also contribute to a change in attitudes, challenging ‘them and us’ thinking. Rather than being stigmatised and seen as somehow alien (see <https://www.talkforhealth.co.uk/the-only-us-campaign/>) people who experience psychosis should find those around them accepting, open-minded and willing to help.

The press coverage was very encouraging, as was the support from other professional bodies and mental health charities. Those welcoming the report from the London launch platform included the President of the UK Royal College of General Practitioners, Professor Mike Pringle, Professor Sir Robin Murray from the Royal College of Psychiatrists, and National Clinical Director for Mental Health Services Dr Geraldine Strathdee, together with the Shadow Government Minister for Mental Health, Luciana Berger MP and representatives from the major mental health charities (Gilchrist, 2015).

Even more encouraging, for me personally at least, has been the overwhelmingly positive response from people who have themselves experienced psychosis or used mental health

services (e.g. Allan, 2014, Hearing Voices Network, 2014). For example, carer and former service user Nicky Hayward (n.d.) described her decades of contact with mental health services, adding 'at any time over all these years I'd have done anything to have been given a handbook like this!' Eleanor Longden, a contributor to the report and a psychologist who was herself diagnosed with schizophrenia in the past, also commented how different things would have been for her had the report been around at the time she was hospitalised (personal communication, 2014). Many other people have emailed or tweeted to say that our document has made a profound difference to them. After years of working all hours on it, these responses have been profoundly moving.

Unsurprisingly given its high profile and its challenge to the status quo, the report has not been without its critics, particularly in the USA. For example, in response to the New York Times coverage, former President of the American Psychiatric Association Jeffrey Lieberman donned a white coat and posted a personal video blog entitled 'What Does the New York Times Have Against Psychiatry?' (Lieberman, 2015). In it he accused us of 'challenging the veracity of diagnoses and giving people ... license to doubt that they may have an illness.' Some commentators (e.g. May & Svanholmer, 2016) have seen such responses as a sign that the report's normalizing message might be a threat to those whose work has been based on the idea of brain diseases requiring aggressive pharmacological treatment. In a similar vein, some other US psychiatrists, for example Allen Frances, have suggested that the report does not address 'real' schizophrenia (Frances & Cooke, 2014).

Others have suggested that the report 'ignores a hundred years of psychoanalytic thought' (e.g. Ferraro, 2014). Some criticisms have been more technical, for example those of our handling of the issue of comparisons between psychological therapies on the one hand and medication on the other. These have been addressed in traditional academic outlets (e.g. Kinderman, McKenna & Laws, 2015).

Some criticisms are well taken. For example, people have pointed out (e.g. Fernando et al, 2014) and we have acknowledged (e.g. Cooke et al, 2015), that the report paid insufficient attention to the specific issues faced by people from black and minority ethnic groups. People from these groups experience discrimination not only within society but within services, and are overrepresented at the 'sharp end' of psychiatry: more likely to be diagnosed with schizophrenia, more likely to experience compulsion and forced medication, less likely to be offered talking therapy. A revised version with improved sections on racism and inequality will be available in due course.

Some (e.g. Ferraro, 2014) have painted the report as an attempt by psychologists, and specifically proponents of CBT for psychosis, to 'sell their wares'. Whilst of course every statement by a professional body contributes to public awareness of what the profession has to offer, our primary motivation was very different. The report is at pains to acknowledge that 'often the most important source of help and support is our network of relationships: friends, family and community': self-help is discussed before that offered by professionals. And far from claiming that psychologists – or indeed any 'experts' – have all the answers or know what is best for people, the report suggests that 'people themselves are the best judges of whether a particular therapy or therapist is helping them.' It advocates humility on the part of professionals, suggesting that the common idea that our job is to tell people what they need should be replaced with a different 'guiding idea':

Mental health is a contested area. The experiences that are sometimes called mental illness, schizophrenia or psychosis are very real. They can cause extreme distress and offering help and support is a vital public service. We know something about the kinds of things that can contribute to these experiences or cause them to be distressing. However, the causes of a particular individual's difficulties are always complex. Our knowledge of what might have contributed, and what might help, is always tentative. Professionals need to respect and work with people's own ideas about what has contributed to their problems. Some people find it helpful to think of their problems as an illness but others do not. Professionals should not promote any one view, or suggest that any one form of help such as medication or psychological therapy is useful for everyone. Instead we need to support people in whatever way they personally find most helpful, and to acknowledge that some people will receive support partly or wholly from outside the mental health system (p.103).

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