

'Schizophrenia': Time to Discard the Diagnosis?

Preliminary findings from the independent Inquiry into the 'Schizophrenia' Label (ISL) finds that over 80% of those who gave evidence believe the diagnosis is damaging and dangerous.

"The label has destroyed my life, friendships, relationships and employment prospects." [Survey respondent]

"The doctor at the hospital kept asking me if I heard voices. I didn't know what she meant by this. Was she checking my hearing, my awareness? Was she using a metaphor? I didn't know. I said yes as I could hear the voices of nurses and patients on the ward down the corridor. That sealed my fate." [Testimony submission]

"When [my son] found that some people recovered he was adamant that he would be one of these and this has helped him to fight for services he needs and to maintain good self-awareness. Therefore largely the label has not been unhelpful -- but very very scary." [Survey respondent]

The independent Inquiry into the 'Schizophrenia' Label (ISL) was launched in April to investigate the usefulness of 'schizophrenia' as a diagnosis and medical condition, and the impact this diagnosis has on people's lives. Since the launch, the Inquiry received evidence from around 500 people in the form of responses to an online survey, testimony submissions via the Inquiry website, comments on Facebook, a focus group in Manchester, and other submissions in the form of articles, personal narratives and memoirs.

The coordinating group and the independent panel are currently collating and examining the evidence. Preliminary results from our survey show that:

- The majority of respondents feel that a diagnosis of 'schizophrenia' is damaging: Over 80% of the respondents said that the diagnosis of 'schizophrenia' makes life more difficult for people diagnosed; 88% think that 'schizophrenia' is associated in the minds of the public with violence against others despite evidence to the contrary.
- 50% thought that they would be treated more harshly by the criminal justice system.
- 60% of respondents believe that 'race' and ethnicity affect the diagnosis of schizophrenia, for a range of reasons including impact of social class, racism and cultural assumptions.
- Well over half (57%) of the respondents do not see 'schizophrenia' as a medical illness and do not think that there is enough scientific evidence to underpin the diagnosis.
- 49% think that medication should be given only if a service user requests this.
- 46% think that the diagnosis of schizophrenia should never be used by professionals in case notes or discussion, with the majority of these arguing that people's own words for their condition or problems should be used.
- Alternatives to diagnosis include working with people's narratives as the basis for support and using techniques developed based on this concept such as those promoted by the Hearing Voices movement and the Finnish Open Dialogue project.

The recent report from the Schizophrenia Commission, headed by the mental health charity Rethink and the Psychosis Research Unit at the Institute of Psychiatry has made 42 recommendations to change the way people diagnosed with schizophrenia are treated. However, our preliminary findings show that the diagnosis itself and its usefulness and validity are under question and may need discarding completely. The initial reading of the evidence submitted to ISL shows that there is no consensus in how we should understand our own and other people's distress and its manifestations, and that it is time to move away from psychiatric diagnoses and support people as fellow human beings rather than as people with a medical illness.

"I know that I experience some kind of 'altered stage' and I wish I could find non-medical language to talk about my experience without having to recite a whole chapter of my life..." [Testimony submission]

"I am in favour of formulating a co-constructed narrative of the service user's problems and their personal meaning in the context of their life experiences. No diagnosis needed!" [Survey respondent]

ISL, supported by over 40 organisations and 250 individuals, has been run on a fully voluntary basis with no external funding. The Inquiry will report fully in the New Year. For more information and to read the testimonies, please visit www.schizophreniainquiry.org.

**The coordinating group
Inquiry into the 'Schizophrenia' Label**