

Inquiry into the 'Schizophrenia' Label (ISL)

Many people are aware that 'schizophrenia' is a controversial diagnosis and its usefulness has been questioned from scientific, cultural, ethical and social perspectives. Western psychiatry has used it as a diagnostic label for 100 years. It is now being spread across the globe.

Whatever the scientific and/or clinical usefulness of 'schizophrenia' as a medical diagnosis, we know from several service user/survivor accounts that a diagnosis of 'schizophrenia' (or 'psychosis') has serious social implications and consequences for people given the label. This is why we are undertaking this inquiry.

We are aware of the 'Schizophrenia Commission', the terms of reference of which assumes that 'schizophrenia' is a valid diagnosis and so considers 'schizophrenia' from a medical and psychiatric system perspective. Our Inquiry takes a service-user/survivor perspective and *focuses on the experience of people given the label and especially the consequences of this.*

ISL will consult with and collect evidence from:

- " people affected by the label 'schizophrenia' (or similar labels such as 'psychosis'), including those who use /have used mental health services, their families, carers and friends
- " those who use these labels to describe mental health problems in other people, and
- " those who have concerns about the use of such labels.

The evidence will be examined by an independent Inquiry Panel. The Panel will produce a report and recommendations and make these accessible in full and summary form online. Findings will be presented to professional, statutory and voluntary sector bodies such as the Department of Health, the Royal College of Psychiatrists, the National Institute for Health and Clinical Excellence (NICE) and mental health charities. Publicity will be sought through press, television and radio. Funding will be sought to continue and build on the work.

So far, we have support from the following organisations:

The Afiya Trust

A national charity that works to reduce inequalities in health and social care provision for people from racialised communities in the UK.

Asylum Collective and Magazine

An international group of people committed to democratic psychiatry.

Catch-a-Fiya

National black and minority ethnic mental health service user network

Launchpad

A mental health service user organisation in Newcastle-upon-Tyne

Maan Somali Mental Health, Sheffield

A community based charity supporting the Somali community and helping NHS and Social Services deliver culturally sensitive services

MindFreedom International

Independent activist coalition united to win human rights and alternatives in mental health

National Survivor User Network (NSUN)

UK network of survivors and users of mental health services.

NEt (North East together)

A network of service users/survivors covering the whole of the North East England

Northumberland, Tyne and Wear Service User and Carer Network (NTWSU&C)

Rights and Wellbeing of Racialised Groups (RawOrg)

A black and minority ethnic (BME) think-tank on mental health and mental health services in UK.

Role Network

A group of service users, survivors and carers covering the North West of England

Shaping Our Lives National User Network

An independent user-controlled organisation, think tank and network

Sharing Voices Bradford

A community development mental health organisation that works within the inner city areas of Bradford.

Soteria Network UK

An international movement of service users, survivors, activists, carers and professionals fighting for more humane, non-coercive mental health services.

World Network of Users and Survivors of Psychiatry (WNUSP)

A network with branches around the world.

And Individuals:

Carolyn Anderson

Vice Chair, National Survivor User Network

Marian Barnes

Professor of Social Policy, University of Brighton. Formerly a Mental Health Act Commissioner

Richard Bentall

Professor of clinical psychology, University of Liverpool

Peter Beresford OBE

Chair, Shaping Our Lives; Professor of social policy, Brunel University

Kamaldeep Bhui

Professor of cultural psychiatry, University of London; President-elect World Association of Cultural Psychiatry

Hanif Bobat

Advisory board member, Journal of Muslim Mental Health; conference advisor for Ethnic Health Initiative

Valerie Boreland

Service user and natural therapist

Mary Boyle

Emeritus professor of clinical psychology, University of East London

Pat Bracken

Consultant psychiatrist and clinical director of mental health services in West Cork, Ireland

Deryck Browne

Researcher and writer in forensic mental health and race issues

Erica Burman

Research professor of psychology and women's studies, Manchester Metropolitan University

Angela Byrne

Clinical psychologist

Alisdair Cameron

Co-founder, NEt (North East together) and team leader at Launchpad

Mick Carpenter

Professor of Social Policy, University of Warwick, Coventry

Patricia Chambers

Service user consultant

Tina Coldham

Mental Health User Consultant/Trainer & Researcher

Steven Coles

Clinical psychologist, Nottinghamshire Healthcare NHS Trust

Anne Cooke

Consultant Clinical Psychologist, Principal Lecturer in Clinical Psychology, Canterbury Christ Church University

Chas de Swiet

Artist and musician; acting chair of Core Arts, Hackney; producer of Liberty Festival and Greenwich & Docklands Festivals

Wesley Dowridge

Deputy chair, Mind in Ealing; carer

Dawn Edge

Academic researcher, University of Manchester

John Eversley

Senior lecturer, London South Bank University and London Metropolitan University

Alison Faulkner

Independent mental health user consultant, trainer and researcher

Nicky Forsythe

Psychotherapist and mental health researcher

Gail A. Hornstein

Professor of Psychology, Mount Holyoke College (Massachusetts, USA)

Claire Gregory

PhD student, De Montfort University and member of National Black Carers and Carers Workers Network

Raza Griffiths

Survivor activist and media trainer

Mel Herdon

Multimedia producer and human rights campaigner

Richard Hallam

Visiting professor of clinical psychology, University of Greenwich

David Harper

Reader in clinical psychology, University of East London

David Henry

Diversity adviser, Rampton Hospital, Notts Healthcare NHS Trust

Mel Herdon

Multimedia producer and human rights campaigner

Sue Holland

Consultant clinical psychologist; Associate Fellow of the British Psychological Society

Guy Holmes

Clinical psychologist: Associate Fellow of the British Psychological Society

Sue Holttum

Senior lecturer, Canterbury Christ Church University

John Hopton

Senior lecturer, University of Manchester

Rhodri Huws

Consultant psychiatrist; Member of Critical Psychiatry Network

David Ingleby

Emeritus Professor of intercultural psychology, Utrecht University; Consultant to the Council of Europe's expert committee on mobility, migration and access to health care.

Sushrut Jadhav

Senior clinical lecturer, Mental health Sciences Unit, University College London

Sumeet Jain

Lecturer in Social Work, University of Edinburgh

Bob Johnson

Consultant psychiatrist specialising in impact of trauma; Member of Critical Psychiatry Network

Mark Johnson

Professor of Diversity in Health & Social Care, De Montfort University Leicester

Lucy Johnstone

Consultant clinical psychologist, Cwm Taf Health Board, South Wales

Frank Keating

Senior lecturer, Royal Holloway University of London

Karen Machin

Mental health campaigner, consultant and researcher

Rufus May

Clinical Psychologist, Bradford District Care Trust

Hugh Middleton

Clinical associate professor, University of Nottingham; Honorary consultant psychiatrist; Member of Critical Psychiatry Network

Joanna Moncrief

Senior lecturer, Department of Mental Health Sciences, University College London; Member of Critical Psychiatry Network

Zenobia Nadirshaw

Consultant clinical psychologist; Associate Fellow of the BPS & Chartered Scientist

James Nazroo

Professor of Sociology and Director, Cathie Marsh Centre, School of Social Science, University of Manchester

Ian Parker

Professor of psychology, Manchester Metropolitan University

Nimisha Patel

Reader in clinical psychology, University of East London

Peter Pearce

Psychotherapist; head of person centred department, Metanoia Institute, London

Lou Pembroke

Voice hearer, activist

Albert Persaud

Co-founder and director, The Centre for Applied Research and Evaluation- International Foundation (careif)

Shulamit Ramon

Mental health research lead, School of Nursing, Midwifery and Social Work, University of Hertfordshire

Mark Rapley

Professor of clinical psychology, University of East London; Member of Critical Psychiatry Network

Aloyse Raptapoulos

Director, 'Cause You Can'

John Read

Professor of psychology, University of Auckland, New Zealand

Alex Reed

Family therapist & mental health nurse working in adult psychiatry (NHS) in Newcastle upon Tyne

Sashi Sashidharan

Consultant psychiatrist; Director, Mental Health Rights

Peter Scott-Blackman

Former CEO of Afiya Trust, London

Dolly Sen

Writer and campaigner; founder, Ascend Mental Health Training and Consultancy

Hari Sewell
Director and founder, HS Consultancy

Mohammad Shabbir
CEO of Sharing Voices Bradford

Debra Shulkes
Survivor activist and editor of *Advocacy Update*

Helen Spandler
Senior research fellow, University of Central Lancashire

Jeanette Stanley
Director of African and Caribbean Mental Health Services, Manchester

Theo Stickley
Associate Professor of Mental Health, University of Nottingham

Derek Summerfield
Consultant psychiatrist, South London & Maudsley NHS Trust; Honorary Senior Lecturer, Institute of Psychiatry, London

Ann-Charlott Timander
PhD student researching mental distress and recovery, Lancaster University

Stephen Tilley
Honorary Fellow, Public Policy Network, School of Social and Political Science, University of Edinburgh

Sami Timimi
Consultant child and adolescent psychiatrist; Visiting professor, Lincoln University; Member of Critical Psychiatry Network

Alison Torn
Associate senior lecturer in psychology, Leeds Trinity University College, Leeds

Rachel Tribe
Professor, University of East London; Fellow, British Psychological Society

Julian Turner
Counsellor and psychotherapist with 25 years' experience working in the mental health field

Why the Inquiry?

We are aware of the increasing unease, even among psychiatrists, about the use 'schizophrenia' or 'psychosis' to describe complex problems of living. More importantly, when these are used as labels attached to people, they can cause serious problems through increasing stigma and undermining the humanity of people given these labels. Indeed, some people seem to suffer from the labels more than they do from other problems of living. Black people in Britain seem to suffer disproportionately in this way.

In December 2011 we noted the launch of a project called 'Schizophrenia Commission' and saw how it was set up without much discussion with service user/survivor organisations and organisations working with black and minority ethnic communities. It seemed to be dominated by a unit that researches 'psychosis' and structured in a narrow medical framework that accepts diagnoses as valid ways of labelling people. We felt that the time was right to launch an inquiry into the 'schizophrenia'

label. And, when we found that such an inquiry was strongly supported by many organisations and individuals, and that many of them were actually willing to do so publicly by allowing us to include their names on our website, we decided to go ahead, raising funds for our expenses as we went along.

Current practice in the UK

The use of the label 'schizophrenia' carries on in psychiatric research, as well as in clinical practice and guidelines, such as those issued by NICE. It thus continues to have a great deal of influence. In view of the problems with the label, psychiatrists have come under pressure to abandon its use as a diagnosis, with the result that 'psychosis' is being used more generally to label the people who would otherwise be labelled with 'schizophrenia'. Hence the inquiry will include the label 'psychosis' as implying 'schizophrenia'.

Concerns about 'schizophrenia' diagnosis

The use of 'schizophrenia' to describe problems of living is problematic for several reasons:

1. 'Schizophrenia' does not seem to mean much (as explanation for mental health problems) to many service users or their carers, relatives and friends.
2. There are historical problems with the diagnosis, which originated 100 years ago at a time when psychiatry was dominated by racist thought, even more than it is today. It grew out of the 19th century idea of 'degeneration' which influenced eugenic theory and practice.
3. The concept of 'schizophrenia' has not proved useful as a basis for research into understanding mental health problems from a biological viewpoint. Its use in international study has confused rather than clarified issues around therapy for, and outcome of, mental health problems.
4. In psychiatry, the use of powerful medication is not necessarily related to a diagnosis of 'schizophrenia'. So the separation of the 'schizophrenia' diagnosis from drug treatment would make the use of medication more transparent, thus reducing its abuse.
5. When looked at transculturally, 'schizophrenia' does not stand up as a useful way of identifying people with problems of living even when these are conceptualised as 'mental' ill health. For example, the experience of hearing voices is widely considered to be a symptom of 'schizophrenia', but many cultures see it differently, sometimes as a spiritual experience.
6. When 'schizophrenia' as a diagnostic concept is used in a multi-ethnic setting, many problems emerge; in Britain it has become conflated with racist oppression, raising questions about the racist nature of the diagnosis itself along with psychiatric stigma.

Find out more

What IS this schizophrenia? Is it time to abandon it as a diagnosis? (Article by Suman Fernando):

<http://www.sumanfernando.com/What%20is%20schizophrenia.pdf>

The case against schizophrenia (Article by the Critical Psychiatry Network):

http://www.criticalpsychiatry.co.uk/index.php?option=com_content&view=article&id=46:the-case-against-schizophrenia&catid=35:documents&Itemid=56

Terms of reference for the Inquiry

In carrying out its work the Inquiry will:

- “ Explore the impact of being given the label ‘schizophrenia’, and the more general one ‘psychosis’, on people given the label
- “ Look at (a) the advantages and disadvantages people experience from receiving the label; (b) the ways in which the criminal justice system affects people once they receive the label; and (c) whether the label is serving any purpose in the present social and political context of UK, taking account of any relevant information from UK and other countries, especially those with non-western cultural heritages in Low and Middle Income range (as per the classification of the World Bank).
- “ Receive evidence from:
 - a) people who have been given the label ‘schizophrenia’ or the more general one ‘psychosis’
 - b) their families , friends and carers
 - c) health and social care professionals involved in systems that are set up to help them and/or control them ‘in the public interest’, especially those involved in enforcing compulsory admission to in-patient settings and compulsory medication while in the community
 - d) people who have concerns about the label.
- “ Examine whether people given the label ‘schizophrenia’, or the more general one ‘psychosis’, experience discrimination or disadvantages as a result of their perceived racial, cultural or socio-economic backgrounds through personal prejudice, institutionalized practices of those working in mental health services, or theories and practices inherent in (western) psychiatry.
- “ Consider in what ways the workforce responsible for providing mental health services could better support and help people given the label ‘schizophrenia’, or more general one ‘psychosis’, to enable them to lead more fulfilling lives.
- “ Look for ways to change or improve the guidance on the ‘treatment’ of people given the label ‘schizophrenia’, or the more general one ‘psychosis’, issued by NICE and other bodies.
- “ Not investigate individual cases or complaints voiced during the inquiry.

Coordinating group

Jan Wallcraft

Jan Wallcraft is a freelance researcher whose work is informed by experience as a mental health service user and activist. She has worked in service user involvement for a range of NGOs. She has a PhD from South Bank University London examining narratives of first experiences with psychiatric hospitalisation. Currently she is a Fellow of Birmingham and Hertfordshire universities, and is engaged in evaluation work on two different self-management programmes for people with long term mental health problems. Her publications include *On Our Own Terms*, a report about the service user/survivor movement, *Healing Minds*, a report on complementary and alternative therapies in mental health, and the *Handbook of Service User Involvement in Mental Health Research*.

Philip Thomas

Philip worked for over twenty years as a consultant psychiatrist in Manchester, North Wales and Bradford. Philip has always held the strong belief that we can understand distress if we take into account culture and history (both individual and group). In 1999, he became a founder member and co-chair of the Critical Psychiatry Network. Although he left clinical work eight years ago, Philip continues to write about critical psychiatry, madness and culture. Until recently, Philip was Chair of

Sharing Voices Bradford, a community development project working with Bradford's diverse communities in the wide field of distress and madness.

Jayasree Kalathil

Jayasree is a researcher and writer. Having encountered psychiatric services in India and in the UK, and spent most of her adult life negotiating six different psychiatric diagnoses, Jayasree has developed a political identity as a survivor. She leads Survivor Research, a virtual collective of individuals interested in promoting user-led perspectives from marginalised communities in the understanding of mental health issues. Jayasree's publications include *Dancing to our own tunes*, which explores black service user involvement, the black women's narratives report *Recovery and Resilience*, and the children's book *The Sackcloth Man*. Jayasree is currently a co-chair of the Social Perspectives Network and the editor of *Open Mind*.

Suman Fernando

Suman has been advocating for better services for black and minority ethnic people and for reform of the psychiatric system for many years. He was a psychiatrist in Enfield for over twenty years and then later became an academic. Now he is honorary professor in the Faculty of Social Sciences and Humanities, London Metropolitan University. Also, he was a member of the Mental Health Act Commission 1988 – 1995. He has written several books in racism, and 'race' and culture issues in mental health and psychiatry.

Inquiry Panel

An independent panel of experts will examine the evidence give to this Inquiry. The panel members:

- " Are not involved in active psychiatric research into the use of medication for treatment of 'mental illness' (because this inevitably involves using labels)
- " Are not working in clinical psychiatry units (and so not subject to pressures and /or conflict of interests)
- " Are residents of the UK
- " Do not have personal or professional connections with the pharmaceutical industry

Colin King - Chair

Colin was given a diagnosis of 'schizophrenia' and medicated while still in his teens but survived that experience to go on to do social work training and become an Approved Social Worker. He did a PhD and was part of a team that co-authored a report called 'Race, Values and Models' for the Mental Health Foundation. Having left social work practice, Colin is now writing a book (on 'schizophrenia') and teaches social workers at Lambeth College in Clapham.

Ann Davies

A trained psychiatric social worker, Ann has taught mental health professionals in the UK and Europe for many years and has researched and published with survivors and users of mental health services on issues of common concern. As Director of the Centre of Excellence in Interdisciplinary Mental Health (CEIMH) at the University of Birmingham, Ann supported the development of survivor generated resources for mental health professional and academic education. She is now Emeritus Professor of Social Work and Mental Health at the University of Birmingham and an Academician of the Academy of Social Sciences. She is an active member of *Suresearch* a network in the Midlands of mental health survivors/service users and their allies.

Chinyere Inyama

A solicitor who has been involved for many years in representing people appealing against sectioning, Chinyere was appointed by the Law Society as an assessor of specialist mental health lawyers and later became a Chairman of Mental Health Review Tribunals. He was a member of the Mental Health Act Commission for several years and involved with many others in lobbying against the changes to the Mental Health Act implemented in 2007. Chinyere has written on race relations, mental health and human rights. He is the first black person to be appointed as a coroner and now works as Coroner at Walthamstow Coroners Court.

Dominic Makuvachuma-Walker

Having survived a racially motivated arson attack and subsequent psychiatric incarceration, Dominic became a campaigner for the rights of black people caught up in the mental health system. For over 15 years, he has brought his personal experience of being a psychiatric survivor and his passion for social justice into his work in survivor activism, including managing the national black and minority ethnic mental health service user network, Catch-a-Fiya. Dominic is currently Vice-Chair of the National Survivor User Network.

David Pilgrim

David is both a clinical psychologist and sociologist with an interest in mental health policy and the philosophy of mental health and 'disorder'. He has worked in acute psychiatric units and been involved in teaching psychologists, social workers and psychiatrists. He left the NHS in 2007 to become an academic and is now Professor of Mental Health Policy at the University of Central Lancashire and Honorary Professor of Clinical Psychology at the University of Liverpool. David's current research interest is in the notion of recovery and the implications for service users of the recently revised mental health act. David has written many articles and several books in the field of sociology and illness.

Premila Trivedi

Survivor campaigner and writer. (Blurb to come)

Work Plan

The inquiry will offer several different methods for people to contribute evidence:

- An online survey
- A publicised call for written evidence
- An opportunity for telephone interviews
- A series of focus groups
- An inquiry event to be organised in March 2011

February–March 2012

- Press launch with launch of website early February
- Opening of Inquiry:
 - Online survey
 - Focus groups
 - Telephone interviews

- Written submissions of evidence
- Event in late March

April 2012

- Evidence collected together and assembled in a dossier
- Inquiry panel consider evidence and invite further evidence as necessary
- Inquiry panel helped by co-ordinating committee draw conclusions and make recommendations

May 2012

- Writing report on the evidence and the Inquiry panel's conclusions

June 2012

- Launch of report

Funding

The Inquiry into the 'Schizophrenia' label has not received any resources from any funding agencies. The Inquiry Panel and the co-ordinating group are providing their services free of charge.

The Inquiry is accepting donations from private individuals to meet the administration and occasional expenses of the project. The fund will be held by NSUN and will be used to reimburse the expenses of people attending meetings and to cover the costs of any public meetings, the website, postage and stationery needed to collect testimony and publicise the Inquiry's work.

Estimated expenses (for which donations are being sought)

- Preparation of website
- Telephone
- Stationery
- Postage
- Travel (e.g. focus groups, Inquiry team, presenters of evidence)
- Refreshments: focus groups, meetings