Issues in Mental Health

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MIND is the leading mental health organisation in England and Wales. It works for a better life for people diagnosed, labelled or treated as mentally ill. It does this through campaigning, influencing government policy, training, education and service provision. Throughout its work MIND reflects its awareness of black and ethnic communities, and draws on the expertise of people with direct experience as providers and users of mental health services.

The points of view expressed in this publication do not necessarily reflect MIND policy.

Experiencing Psychiatry

Users' Views of Services

**Anne Rogers
David Pilgrim
and
Ron Lacey**

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To all the users who made this book possible

FOOL: . . . as a madman's epistles are no gospels, so it matters little when they are delivered.

OLIVIA: How now! art thou mad?

FOOL: No madam, I do but read madness: and your ladyship will have it as it ought to be, you must allow its voice.

Shakespeare, *Twelfth Night*, Act V, Scene 1

Men will always be mad and those who think they can cure them are the maddest of all.

Voltaire, Letter 1762

I have myself spent nine years in a lunatic asylum and have never suffered from the obsession of wanting to kill myself; but I know that each conversation with a psychiatrist in the morning made me want to hang myself because I knew I could not strangle him.

Antonin Artaud, 1896–1948

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Preface

The survey on which this book is based was undertaken during 1990 by local MIND associations, mental health self advocacy groups and workers in statutory mental health services. The survey and the analysis of the results were done in collaboration by MIND and Roehampton Institute, London. The questionnaire used examined mental health services in England and Wales through the eyes of people with substantial experience of being at the receiving end of those services. Every one of the 516 people who took part in the research had received at least one period of in-patient treatment in a psychiatric hospital. The questionnaire for the survey was designed on the basis of discussions with psychiatric service users which defined the issues and set the agenda for the survey. This agenda was also shaped by the nature and frequency of enquiries and complaints received by MIND's national and local advice and information services.

The People First survey was a development of a survey amongst chronic tranquilliser users undertaken jointly by MIND and the BBC in 1984. MIND's national and local advice services had been receiving a large volume of enquiries from people experiencing problems with benzodiazepine minor tranquillisers. They complained of side-effects and of difficulties they were experiencing in withdrawing from them. Many people complained that doctors were either ignoring their anxieties about the drugs or dismissing them as symptoms of their problems. A literature search revealed a marked association between the nature of the problems reported to MIND's advice services and reports of adverse effects and the risks of dependence associated with benzodiazepine reported by a substantial body of research. These findings led to MIND launching a sustained public campaign to focus attention on the problems generated by the over-prescription and misuse of benzodiazepine tranquillisers. MIND's special report, *Minor Tranquillisers, Hard Facts-Hard Choices*,¹ launched the campaign and generated widespread media interest in the issues. In 1983 a popular BBC consumer programme reported the stories of three people who said they had become

dependent on tranquillisers, which led to more than 3000 letters being received by the programme from people with similar problems. The programme approached MIND with a view to setting up a national telephone counselling service to help people with tranquilliser problems. However, MIND was reluctant to engage in such a massive undertaking and had severe reservations as to the potential value of a telephone counselling approach to the complex problems of so many people. In the light of these reservations it was decided to conduct a survey amongst those who had written to the 'That's Life!' programme. Questionnaires were sent to 3000 viewers and 2150 valid responses were returned. The results of the MIND 'That's Life!' survey were published by BBC Publications in 1985² with the expressed intention of putting the experiences of people who had used the drugs into the centre of the public debate. The publicity surrounding minor tranquillisers increased the number of enquiries concerning other types of psychiatric treatment which led to MIND publishing further special reports on other drugs and ECT.³

MIND is a 'broad church' which encompasses many varieties and shades of opinion. There are those who subscribe to the medical model of mental illness and its treatment, there are others who are sceptical of the model and an increasingly influential body of users who not only reject the medical model but are vociferously hostile to it. Thus one of the purposes of the People First survey was to reach out to people who had had, or were receiving, mainstream mental health services to inform the sometimes vigorous debates which were taking place within MIND. The major criterion for selecting respondents for the survey was the experience of at least one period of treatment in a psychiatric hospital as an in-patient. We were particularly concerned to seek the views and experiences of people whose needs would be perceived as being at the severe end of the continuum, needs which have traditionally been defined by others, (usually by people with a financial or professional interest in providing mental health services.) The survey was conducted in a climate of rapid change in the location if not the nature of mental health services. Hospitals were closing and people were being discharged into the community. Some patients seem to have rejected whatever services that may have been available to them, whilst others have made the transition with few problems. There has been a great deal of media coverage of the consequences of

the inadequate services in the community, and no shortage of people prepared to join in the public debate as to what should be done for the 'mentally ill'. There have been calls to halt mental hospital closures until such time as alternative services become available. However the voices of those for whom mental health services are ostensibly designed have been noticeably absent in the debate. This book represents an attempt to provide a medium through which some of these voices may be heard.

The book is structured in a particular way to try to provide a coherent account of the main findings of the survey. Because of space we have been unable to present every nuance of the data. However, no major finding from the analysis has been omitted. Also we have not only offered the reader a glimpse of these findings in their bald state. They have been put into a context of other work done. For instance at the beginning, even before we get on to our data, we summarise the ways in which existing researchers have dealt with the views of psychiatric patients. Then at the beginning of each chapter, we put the findings into the context of other literature.

After the review of existing work on the patient's view, the ways in which users saw their mental health problem are described and discussed. This is followed by their views of the professionals they encountered. The experience of life both inside and outside of psychiatric facilities is then addressed. Two chapters are then given over to organising our findings on treatment and the respondents' experience of informed consent to that treatment.

Finally, we have a concluding chapter which draws out some policy implications of the data as a whole. A methodological appendix is provided in order to provide a full account of the way in which the survey was conducted and our thoughts on the strengths and weaknesses of the sample of patients and ex-patients we accessed.

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References

1. *Minor Tranquillisers: Hard Facts – Hard Choices* (London: MIND, 1982).
2. Lacey, R. and Woodward, S., *That's Life Survey on Tranquillisers* (London: BBC Publications, 1985).
3. *Antidepressants: First Choice or Last Resort?* (1984); *Major Tranquillisers: The Price of Tranquillity* (1985); *Lithium Therapy: Questions of Balance* (1985); *ECT: Pros, Cons and Consequences* (1988).

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