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Introduction

This is a book about psychiatric drugs written from a fresh perspective; that of people who have taken them. My interest in the subject stems from my own experience of being on psychiatric drugs and many years of discussing them with friends and colleagues in the mental health system survivor or service users' movement. Much of the content of this book relies on people's willingness to talk openly about their experiences, and in my working life as a trainer, writer, researcher and consultant on issues of concern to service users, I developed the principle of not asking people to share information I wasn't prepared to share myself, so I will begin this introduction with a brief account of my own psychiatric drugs story.

After an early childhood encounter with barbiturates, from the ages of 19 to 21 I was on tranquillisers and antidepressants. It was a long time ago, in the 1970s, and a small story compared with those of people who have been on them (or on and off them) for decades, but for me it was a major event which had a profound effect on the rest of my life.

The prescribing and taking of psychiatric drugs is always about more than a chemical and a brain, and this is illustrated by the circumstances in which I started taking them. I had failed to study for university exams and was sent to a doctor who would assess whether I was simply lazy (bad) or ill (mad). The prescription of antidepressants was part of a diagnostic package that legitimised my failure to take the exams and gave me another opportunity. Soon I was on tranquillisers as well but I never did find the concentration and will to study. After a few months I had a brief adventure, working in a restaurant in Florida in the USA. Life was so busy and demanding that I kept forgetting to take my pills and stopped them altogether. But after a relationship went badly I went back on my pills and returned to England. My attempts to get my life on track seemed thwarted at every turn and I ended up as an informal day patient. I happened to live within walking distance of one of the old asylums – Park Prewitt in Basingstoke, southern England – and would go there to take part in occupational therapy.

The drugs I was taking hadn't made a big impact on me until I was taken off the tricyclic antidepressant and put on another type of

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antidepressant rarely used now called a monoamine-oxidase inhibitor (MAOI). These had a strong sedative effect on me. One day my parents went out to work, came back and I hadn't moved. They took me up to the hospital and the doctor decided I must be on too high a dose and reduced it. By this time I was sinking into the role of chronic mental patient, but all this changed when I was told that as the drugs hadn't worked I was to have ECT (electroconvulsive therapy).

Up until this time I had done what I was told but, having seen the effects of ECT on fellow patients, I somehow found the ability to refuse and stopped going to the hospital. My family doctor suggested that instead I should move to a therapeutic community called Cassel Hospital, where I would live with other young people and get help with my problems. I agreed, was assessed and accepted, and told I had to come off my drugs before I moved in. I was given no warnings or advice about coming off the drugs, stopped them overnight and felt nothing worse than a bit shaky. It wasn't until the 1980s that I became aware that tranquillisers could be highly addictive and only when researching for this book did I discover that coming off MAOI antidepressants abruptly can cause life-threatening reactions (Glenmullen 2005, pp. 211–12). Had I encountered difficulties in stopping these drugs (and lived!) I might well have gone back on them and my life could have taken a very different course.

Instead I spent eight months living in the therapeutic community before attempting, with eventual success, to live independently and build a new life for myself. I hadn't completely bought in to the idea of not using psychiatric drugs though. I have memories from the period after I left the Cassel of lying in bed phoning A&E (accident and emergency) departments asking for tranquillisers only to be defeated by their refusal to dispatch supplies by courier. As things turned out, though, the only psychiatric drugs I have ingested since then have been the occasional tranquilliser, prescribed for emergency pain relief.

Even within this short story are themes that regularly crop up in people's accounts of taking psychiatric drugs: passivity, indifference, stopping and starting, over-prescribing, adverse effects, ignorance about coming off them and insecurity about managing without them. But whereas my experience of drugs was basically negative, others have more positive stories to tell. Twenty five years of being involved in the movement of service users or survivors of psychiatry has taught me that for every person who says their life has been ruined by psychiatric drugs there is someone who believes they have been saved by them, and many more who just don't know, who have been taking them for

years and wonder if their lives would have been better or worse if they had been free of them.

Listening to Service Users

When I was a mental patient no-one was interested in what I had to say about the treatment I received. This was partly to do with the paternalism of the medical profession – ‘doctor knows best’ – and applied equally to other branches of medicine. Mental hospitals were strict hierarchies, with psychiatrists on top and everyone telling the people below them what to do until you got to the patient at the bottom. Mental patients were, anyway, considered too irrational to have valid views about their treatment or the circumstances of their lives.

But in the UK, the 1980s were a time of upheaval in mental health services, as the old asylums were replaced by community facilities such as day centres and supported housing projects. People who had been hidden away in institutions found themselves living in ordinary communities with a degree of independence. These changes may have contributed to a situation in which users of mental health services felt more able to advocate on their own behalf. Self-organisation wasn't new, but began to flourish more than ever before. The UK-wide organisation, Survivors Speak Out, was formed and was soon campaigning against proposals to extend compulsory treatment to include some people living in the community. Local organisations set up patients' councils and advocacy projects (Survivor/User History Group 2008).

This self-organisation reflected and benefited from similar activities that were already under way elsewhere. In the USA the closing of asylums had begun earlier and in her book, *On Our Own* (1988), first published in 1977, Judi Chamberlain described community projects there and in Canada that were controlled by service users. In the Netherlands, patients' councils were well established and people who were organising them helped to get them started in the UK (Read & Wallcraft 1994).

Another strand of action was more focused on primary care. People who had been taking tranquillisers, such as diazepam (Valium), for years were realising they had become addicted to them despite denials from drug companies and doctors. They formed self-help groups to support each other to get off the drugs and spoke out in the media (Lacey and Woodward 1985; Medawar 1992).

The UK NHS and Community Care Act 1990 required service providers to consult with users of their services and their ‘carers’ (meaning

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family members). With associated funding for local groups becoming more available this gave a new impetus to the activities of service users. But with it came a different emphasis. Instead of deciding on their own priorities and campaigns, service users were being asked to respond to more limited agendas set by bureaucratic organisations.

'User involvement', as it came to be known, has been far from an unqualified success (Read 2001; Wallcraft, Read & Sweeney 2003; Campbell 2005) but has established the legitimacy of service users' views. A succession of policy directives has introduced user involvement into every aspect of the planning and provision of mental health services (Department of Health 1999), the education and training professionals (Postgraduate Medical Education and Training Board 2008) and people's own treatment plans through the Care Programme Approach, introduced in 1991 (Department of Health 2008).

Through their own initiative and the encouragement of others service users have also involved themselves in just about every other aspect of mental health services, from running self-help groups to setting up crisis houses, and from evaluating services to organising activities to promote their own emotional well-being (Wallcraft, Read & Sweeney 2003).

The publication of this book is a product of these last 20 years and more of intense and continuous activity by service users, and by professionals, policy makers and politicians promoting user involvement. Funding from the Department of Health for the original research – Coping with Coming Off – included here, and the decision by a leading mental health organisation, Mind, to commission the research from a group of current and former service users reflect and help to create a climate in which the contribution of 'experts by experience' is becoming more welcomed and expected.

For an academic publisher to produce a book written by someone whose expertise stems from his personal experience of the mental health system and immersion in the service users' movement rather than formal training and academic qualifications is a bold step, but one that can be justified in an era in which mental health professionals are expected to familiarise themselves with the views of service users.

Service Users and Research

Another aspect of the mental health world to which service users are making an increasing contribution is research. We have moved from

being merely the subjects of research to participants who are asked to describe our experiences and say what we think, and on to initiating and carrying out research projects.

Two psychiatrists, Patrick Bracken and Philip Thomas, identify why it matters that we have done this. In their book, *Postpsychiatry: Mental Health in a Postmodern World* (2005, p. 51), they point out that user-led research in mental health is unique. There is no equivalent in general medicine. They suggest that it has developed 'out of frustration with the failure of professional-led research to engage with issues and outcomes that are important to service users'.

User-led research has been an especially strong feature of service-user activity in the UK, exemplified by two projects, Strategies for Living, based at the Mental Health Foundation and SURE (Service User Research Enterprise) with the Institute of Psychiatry.

Nearly all research into psychiatric drugs is initiated and funded by drug companies and their priority is to prove that their products are safe and effective in order to be able to bring them on to the market and sell them in profitable amounts. To prove effectiveness they have to be able to demonstrate that the drugs reduce symptoms associated with the various diagnoses of mental illness without also producing unacceptable adverse effects. In practice these drugs trials only measure their short term effects.

People who take psychiatric drugs want to know these things, but may be equally concerned with others. For example, they may want to know what harm taking them may do over time, how long they have to take them for and whether they will have trouble stopping them – information that is under-researched and may be slow to emerge. Above all they want to know if the overall effect of taking psychiatric drugs is likely to have a positive or negative impact on their lives. Professionals who prescribe them, make sure people are taking them and support people who are on them should, of course, be equally interested in their overall impact.

Finding answers to these questions is not straightforward. Over time there are many factors that influence people's mental and physical health. How to identify the effects of one intervention? There is no perfect method, but people with the lived experience of that intervention can make a strong contribution. When the intervention is a psychiatric drug and the people taking it are diagnosed as mentally ill, the issue of credibility arises. But although our views were once deemed to be inevitably irrational because of our 'madness' or 'neurosis', we have now established credibility as commentators on our own lives. The annual survey of service users' views carried out by the Healthcare Commission

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(Healthcare Commission 2008a) as a measure of the performance of providers of mental health services is testament to our newfound status.

But issues of credibility remain. The only way to systematically gather, analyse and present people's accounts of their experience is through well-designed surveys. But surveys do not have a high status in the traditional world of academic research. For example, in the original hierarchy of 'clinical evidence' considered by NICE (the National Institute for Health and Clinical Excellence) when evaluating treatments, they did not feature at all (Eccles & Mason, cited in Snowden 2008, p. 92). If our views have credibility but the only method of ascertaining them does not, then we are still sidelined and a contribution to the understanding of psychiatric drugs is lost.

All research methods have their limitations, including the so-called 'gold standard' of research: the double-blind, randomised controlled trial. Assessors of evidence could do with taking on board the extensive criticisms of this method (discussed in Chapter 1) and being more open to findings from surveys. Similarly, when considering complex interactions, there is a role for the qualitative data that emerge from in-depth interviews as well as quantitative data – numbers and percentages.

Few mental health workers will have ever seen a survey of people's views on their experiences of psychiatric drugs. Yet without this information there are gaping holes in our picture of how much they affect people's mental and emotional well-being. As David Healy (2005, p. xii), a renowned expert on psychiatric drugs and critic of drug companies, has said, 'The final arbiter of whether psychotropic medication is useful or not is the taker.'

The Coping with Coming Off Research

The core of this book comprises three chapters on a research project looking at people's experiences of trying to come off their medication. This may appear to be rather specific for a book intended for people who want to educate themselves more generally about psychiatric drugs. But there are two reasons for including it. First, although the focus is coming off drugs, this includes much valuable description of interactions between the mental health workers who prescribe the drugs and try to ensure they are taken and the people they prescribe them to. Secondly, the issues of withdrawal from psychiatric drugs are vitally important to service users. Nearly everyone who takes a psychiatric drug will stop taking it at some point. Will they get ill again? Will they find

they have become addicted to it? Will the doctor agree to them stopping and, if not, should they do it anyway? These crucial questions are given relatively little attention in the literature about psychiatric drugs.

Coping with Coming Off (CWCO) is an in-depth survey of just over 200 people. The most comprehensive survey of users' views and experiences is by the Scottish Association for Mental Health and published as "*All you need to know?*" (SAMH 2004). Over 1000 people filled in questionnaires about every aspect of their recent experience of psychiatric drugs. With these numbers it is possible to compare people's experiences of different drugs within the same type. Material from this survey has been used to augment that from CWCO.

Relevance to Current Trends

Mental health services are changing. In England, since the publication of the *National Service Framework for Mental Health* in 1999 (Department of Health 1999) there have been a host of initiatives aimed at providing more effective community-based services. At the same time changes affecting all health services are taking place, with the emphasis on providing patients with more choice. Policy doesn't always translate into practice, as exemplified by difficulties in involving people in decisions about their own care and treatment through the care-programme approach. In 2008 a survey found that only 40 per cent of people with a care plan said they had definitely been involved in deciding it, with 36 per cent saying they had been involved to some extent and 24 per cent saying they had not been involved at all (Healthcare Commission 2008a, tables section F).

But although the rhetoric may be ahead of the reality, there are so many policy documents, projects and campaigns that it is beginning to seem inevitable that there will be significant changes in relationships between doctors and patients, with the prescribing of psychiatric drugs (or decisions not to prescribe) becoming more often more of a joint decision between doctor and patient.

Three initiatives in particular are indicative of these changing roles. These are:

- guidelines on shared decision-making and adherence in prescribing;
- new roles for mental health workers; and
- widespread adoption of the recovery approach in mental health services.

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Doctors prescribing medicines which their patients don't take has been a common phenomenon, not restricted to the mental health world. Traditionally this behaviour by patients has been known as non-compliance and been viewed by health workers as mistaken and in need of correction. But a new approach has been developed which acknowledges patients' rights to discuss and negotiate with prescribers and ultimately to make their own decisions.

A NICE clinical guideline, *Medicines Adherence: Involving patients in decisions about prescribed medicines and supporting adherence* (2009a), describes a new and more equal relationship between prescribers and patients which emphasises the importance of prescribers listening to patients' concerns about medication and seeking to reach agreement with them. (There is more about shared decision-making and adherence in Chapter 1.)

In England, the roles of mental health workers are changing. One clear, obvious and definite change is the extension of 'non-medical' prescribing. From 2006 suitably qualified nurses and pharmacists have been able to independently prescribe nearly all licensed medicines (Department of Health, 2006a, p. 4). Similar arrangements have since been introduced in the rest of the UK.

In other ways, also, professional hierarchies and barriers are breaking down. A Department of Health initiative, 'New Ways of Working' (Department of Health 2007, p. 11), is intended to enhance team working and, for example, encourages staff 'to share knowledge, skills and competences across professional and practitioner boundaries'. Dr Joanna Bennett, Senior Research Fellow at the Sainsbury Centre for Mental Health, suggests (2008, p. 122) that mental health practitioners – and not just those with prescribing powers – need 'knowledge of the effectiveness of medication and at least a working knowledge of psychopharmacology' to enable 'discussion amongst the multidisciplinary team members and the service user on the most effective use of medication and the integration of different treatment approaches'. Gone are the days when mental health workers simply left the business of medication to doctors.

The Department of Health has produced a leaflet to explain 'New Ways of Working' to patients and carers (Department of Health 2007). Among the reasons listed for bringing in this initiative are: 'it moves away from attitudes of dominance and control' and 'service users can be seen as a whole person and not just an illness'.

The third of these current trends is the widespread adoption of the recovery approach. It can be an elusive concept and is not necessarily

about 'cure' but more about leading the fullest life you possibly can. The recovery approach emphasises the significance of hope for people diagnosed with long-term conditions. In mental health, avoiding passivity and taking charge of your own destiny are important components that challenge aspects of traditional services.

Pat Deegan, a service user from the USA, should be credited with having done much to develop the recovery approach. New Zealand and the state of Wisconsin in the USA have pioneered the adoption of this approach by services (New Zealand Mental Health Commission 2001; Jacobson, cited in SCIE 2007, p. 14). Now it is achieving widespread acceptance in the UK. For example, a review of mental health nursing, *From values to action* (Department of Health 2006b, p. 4), states that 'Mental health nursing should incorporate the broad principles of the Recovery Approach into every aspect of their practice'. The Royal College of Psychiatrists is also supporting adoption of the recovery approach and is committed to training psychiatrists to work in this way (2008, p. 27).

The recovery approach does not include a specific view on psychiatric drugs but does emphasise choice, with professionals being more willing to take the lead from patients. The Royal College of Psychiatrists (2008, p. 29) goes as far as to say that mental health workers 'should support people in trying to achieve the goals they set for themselves, even if they believe the goals are not realistic'. Presumably this includes goals about living without medication.

These three trends are consistent with each other, with service-user action and involvement, and the Care Programme Approach. All have implications for how decisions about psychiatric drugs are made. People who have been non-compliant with medication regimes have to be respected, negotiated with and their right to refuse acknowledged.

Except, of course, mental health legislation allows the service user to be overruled in certain circumstances. A challenge for services working in new ways is to not allow this power to contaminate situations in which it doesn't apply.

Purpose and Scope of the Book

I have written this book primarily for people studying to work in mental health services. I hope it will help them to engage in the confusing and contentious world of use of psychiatric drugs from a perspective that starts with the experiences and concerns of service users.

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Everyone involved in providing mental health services in the statutory and voluntary (non-governmental) services needs to understand the place of psychiatric drugs in the lives of the people with whom they work. This includes staff who have most day-to-day contact with service users and who potentially have the best understanding of how they are experiencing medication and how they feel about it.

Throughout the book are boxes containing ideas for critical reflection. These can be used by students on their own or in groups. Ideally a student should make notes and use them to contribute to a discussion.

No prior knowledge of psychiatric drugs is required to understand this book. There is a brief guide to the different types in Chapter 1. When I have needed to use medical terms I have explained them.

I hope that this book will also find a wider audience. It is not a conventional basic guide and offers something new to anyone involved in the mental health field. The CWCO research offers new angles on old problems that are relevant to current issues such as choice, recovery and listening to service users. There are implications for policy at local and national (or state) level.

It is not written as a self-help book but does include material that will be of interest to anyone who is thinking about coming off their psychiatric drugs and which will help them to make informed decisions about whether and how to proceed. This material will also benefit anyone who takes on the responsibility of advising and supporting someone who is thinking of stopping their drugs. I suggest also that people who have family members and friends on psychiatric drugs could benefit from reading it.

I have been unable to locate any significant surveys of people's experiences and views of psychiatric drugs from outside the UK. But I think the UK research has relevance for any country where psychiatric drugs are used. I have taken other research and sources of information from wherever I can find them. They include much from the USA. Most of the organisations, regulations and guidelines mentioned are from the UK and I have not assumed that all readers are familiar with them.

I do not attempt to explain the biochemical action of drugs on the brain and rest of the body. Instead I focus on why and how they are used, the people who take them and how they deal with the people who prescribe them and monitor their use.

Also beyond the scope of this book is the use of drugs with young people under 18, for whom different guidelines apply.

Structure of the Book

Chapter 1 sets the scene. It begins with an overview of the place of drug treatments in mental health services and introduces the drugs most commonly used in psychiatry. It then looks at how they are supposed to be used according to current guidance, how current practice diverges from these guidelines and at criticisms of the guidelines.

Then I identify the following five key issues concerning the use of psychiatric drugs:

1. Adverse effects of psychiatric drugs: What are their range, severity and frequency, and what impact do they have on the lives of people taking them?
2. Choice and compulsion: What rights do people have to be informed about and exercise choice over drugs they are prescribed, what powers do psychiatrists have to force people to take drugs, and how are the tensions between choice and compulsion played out in practice?
3. People from black and minority ethnic (BME) communities: What are the issues about over-prescribing of psychiatric drugs for people in BME communities, what is being done about them, and what more could be done?
4. The rise and possible fall of SSRI antidepressants: Some of the problems with drugs being manufactured and marketed for profit are epitomised by the way the popularity of Prozac and similar antidepressants has outweighed their actual effectiveness and safety. How did this occur, and what is the future for these drugs?
5. Effectiveness: What are the challenges in measuring the effectiveness of psychiatric drugs, and is there an evidence base to justify their dominant position in the treatment of mental distress?

Chapter 2 re-examines these key issues from the perspectives of people who have taken the drugs. By drawing on key surveys from the UK it brings in a perspective that is usually lacking in discussion and decision making about psychiatric drugs. From this we learn about the impact of adverse effects on people's lives and what they are prepared to tolerate if they feel they are benefiting from the drugs. We see people's assessments of how good mental health workers are at giving information about what they can expect from taking psychiatric drugs, with examples of good and bad practice. Service users from BME communities talk about how they feel cajoled into taking drugs they don't like and how they perceive this as racism. People who have

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taken fluoxetine and similar drugs give their verdicts, and we see how they are compared with other approaches, such as talking treatments. Finally, we see how people rate all the different types of psychiatric drugs for overall helpfulness and how people taking the same drugs can experience them very differently.

In Chapter 3 we look at the three stages of coming off, or attempting to come off, psychiatric drugs. These start with the decision to come off. What does clinical guidance say about how long people should stay on their medication, and what happens in practice? The second stage is what people experience during the process of coming off. Included here is a discussion of the concepts and language of addiction and dependence, and a look at how to distinguish between symptoms returning as the effects of drugs wear off and withdrawal syndromes. The third stage is about what happens to people who succeed in coming off psychiatric drugs. Do they tend to flourish, relapse, or carry on much as before?

This is followed by three chapters based on the Coping with Coming Off (CWCO) research. In Chapter 4 I describe how the research was carried out and who the people were who participated. Then there is a detailed look at people's reasons for trying to come off their drugs. We also see how they went about making the decision and, in particular, how they did or did not involve their doctors and their reasons why. Chapter 5 includes material on the experience of trying to come off – how hard it was and what support people received. We also look at what factors influenced success; factors such as whether or not they told their doctor, what drugs they were on, and how long they had been taking them for. Then we see what benefits were felt by people who succeeded and what lessons were learned by people who didn't succeed.

One of the most significant themes that emerges from the research is the tension between doctors and patients diagnosed with schizophrenia or bipolar disorder about whether they should stay on their medication. In Chapter 6, this is explored in depth, with the stories of three participants in the research used to illustrate how these tensions are played out and can sometimes be resolved.

In Chapter 7 I return to the five key issues, look further at how they are informed by the experiences and views of people taking psychiatric drugs, and make some suggestions for improving practice. The conclusion draws together hopeful thoughts about a new relationship between people who prescribe, administer and monitor medication and the people who they may prescribe it for.

Appendix 1 lists resources for people wanting practical guidance about coming off psychiatric drugs and Appendix 2 brings

together some statistics to show what proportions of people experience unwanted effects when stopping different drugs.

Language

Anyone writing about mental health issues indicates their own orientation and beliefs by the language they use. The choices I make here reflect my involvement in the service users (or should that be survivors?) movement. Above all, we want to be seen as people and not be defined by diagnosis. We are not schizophrenics but people diagnosed with schizophrenia, which includes people who do or don't accept the validity of the diagnosis. I sometimes resort to 'service user' and 'patient' for conciseness and to avoid repetition, but have generally preferred 'people who have taken psychiatric drugs' and similar terms.

I refer to mental distress rather than mental illness because it is a more inclusive term as it doesn't assume a medical explanation. But I have used some contestable words and phrases from psychiatry without comment or inverted commas simply for convenience and clarity of text. They include psychosis and non-compliant. Other choices of language – such as neuroleptic or antipsychotic and withdrawal syndrome or discontinuation syndrome – I explain when they first occur.

I have used the general (generic) names for drugs, but if a drug is better known by its brand name I have included it in brackets the first time the drug is mentioned in each chapter, for example, 'fluoxetine (Prozac)'.

I use the terms 'over-prescribing' and 'over-medicating' several times and intend them to mean any of the following: prescribing drugs in higher doses or for longer than recommended in guidelines without justification; prescribing drugs in combinations that are not recommended in guidelines without justification; prescribing drugs at doses that don't take into account the possibility of the person metabolising them more slowly than average; continuing to prescribe drugs at doses or of types that are causing distress to the patient; wrongly prescribing neuroleptics or antimanic because the person has been misdiagnosed; prescribing drugs when other suitable courses of action exist which are preferred by the patient.

When I have reproduced material from elsewhere I have kept the original language.

A variety of terms and conventions are used when referring to people's skin colour or ethnic group. When referring to a particular

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report or article I have kept the terms and conventions used in it even when not quoting directly. I think and hope the inconsistency of language that results is less confusing than altering language from other sources.

Critical Reflection Box 1.1**Beliefs about Psychiatric Drugs**

Take some time to examine your personal beliefs about psychiatric drugs by trying to answer the following questions. Don't be put off if you feel you don't know enough:

1. Think of the person you know best who has taken psychiatric drugs. What impact do you think they have made on that person's life? Do you and that person have the same opinion about them?
2. Can you think of someone for whom psychiatric drugs appear to have done more good than harm? If so, on what are you basing that judgement?
3. Can you think of an example of someone for whom psychiatric drugs appear to have done more harm than good? If so, on what are you basing that judgement?
4. Can you think of someone who isn't on psychiatric drugs who you think would benefit from taking them? What would you like to say to them?
5. Can you think of someone who is on psychiatric drugs who you think would benefit from coming off them? What would you like to say to them?
6. What has influenced your views about psychiatric drugs? Some possibilities are:
 - (a) taking them yourself
 - (b) seeing their effects on other people
 - (c) professional training
 - (d) your personal beliefs about dealing with life's challenges
 - (e) other
7. And finally, how do you rate psychiatric drugs overall for helpfulness?

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