

Mental Health Outcome Measures

In memory of Judi Chamberlain and John K. Wing,
who have both contributed so much to our understanding of which outcomes
are most important to assess

Mental Health Outcome Measures

Third edition

Edited by Graham Thornicroft
and Michele Tansella

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Foreword

In my years as a junior doctor in a general medical ward, I was often impressed by the gap between what the patient had originally complained of and the leads followed by the medical team in pursuing an unexpected abnormality in a routine investigation, which in fact had little relevance to the patient's actual concerns. Later, while training in psychiatry, I was interested to observe how clinical psychiatry followed a similar pattern: procedures were carried out which made sense to the clinical team but had little relevance to the patient.

This new edition of Thornicroft and Tansella's review of outcome measures marks an important step in the development of mental health services, in that major emphasis is now given to aspects of outcome that are valued by the service users themselves. In Chapter 1, Kabir and Wykes review this important field, and point out that users are more interested in recovery and happiness than in remission of presenting symptoms. Even measures of 'satisfaction with services' that are not devised in collaboration with users come in for a critical examination.

However, another new area of interest, identified by the editors in the Introduction, is indeed the currently fashionable concept of 'recovery', which gets an extended treatment in Chapter 4. As a retired psychiatrist, I found the new enthusiasm for full recovery rather strange, as it appears to imply that such an aim is something new and (worse still) always achievable. However, it emerges from Chapter 4 that there are in fact a range of meanings ascribed to the concept of 'recovery', ranging from the fairly modest aim of living as well as possible to the more utopian one of having a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination.

Failure to achieve 'full recovery' may not be due either to incompetence on the part of the clinician or to lack of motivation on the part of the patient; it is often due to the severity of the underlying disorder. It seems to me important that, rather than inwardly apologising to themselves for incomplete recovery, clinicians should adapt their energies to enabling users to achieve more personal autonomy. But for the most disabled patients with long-term

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severe mental disorders, enabling them to make personal choices about what they eat and giving them a more active involvement in the choices they can make in their personal lives are worthy objectives. An example of this is given in Fig. 4.1 (p. 71), where a user sets her own goals for an improvement in her autonomy.

This new edition is indispensable to researchers in health services research, as it is strikingly comprehensive, with every aspect of outcome covered, and includes all the most recent developments in the field. New measures are constantly being developed, and old measures are often re-evaluated, so that even those chapters that are similar to those in previous editions have new and important information. An example of this appears in Chapter 2, on statistical methods for measuring outcomes. Novices to the field are stepping over a statistical minefield when they rely on single, small evaluations – Dunn emphasises the importance of multicentre trials in order to achieve adequate power.

The book does what needs to be done – it brings the whole field up to date, and in doing so expands our horizons.

David Goldberg
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Foreword

Many different themes dominate the current literature on mental health services. Services should facilitate meaningful outcomes. The mission should be recovery. Interventions should be evidence based. Care should be client centred or self-directed. The mental health system should diminish stigma and foster social inclusion. Information technology should enhance efficiency. And many more! Each of these represents an endangered species. Why endangered? Simply put, philosophical movements easily become transient fads when they are not grounded in measures, numbers and data. Ideas, goals, guidelines, missions, benchmarks and plans require measurement to attain any hope of enduring reality. If nothing is measured, nothing changes. Instead, the next year brings a new commitment to yet another banner idea.

Mental health has long suffered from lack of measurement – a tradition extending back to the days when lack of measurement was valorised by clinicians who argued that the entire enterprise was too personal, ethereal or mystical to measure. Mental healthcare has, though, emerged from the dark ages. Although we still lack clear biological and physiological standards, measurement must be at the core of what we do. And measurement is no simple matter.

As the authors of the following chapters argue, measurement in mental health is serious and arduous work. We need measures that are reliable and valid, that address meaningful processes and outcomes, that uphold and reinforce our values, and that enhance rather than impede the enterprise of behavioural health. Developing, refining, testing, comparing and instantiating such measures are essential tasks if the field is to move forwards, rather than recycle old ideas in new terminology.

I commend the editors for their persistent efforts to encourage high-quality research. The chapters herein describe progress on many important fronts.

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Preface: an evolving perspective of mental health outcome measures

Since the appearance of the two previous editions of *Mental Health Outcome Measures* (first published by Springer Verlag in 1996, with a second edition published by the Royal College of Psychiatrists in 2001), there have been several intriguing developments in the field. First, an even wider range of important outcome domains are now measurable using well standardised instruments than were measurable before. Second, a greater emphasis upon positive outcomes has evolved (for example referring to the concept of recovery) among researchers, service users and clinicians. Third, the voice of the service user/consumer is now centre stage to a much greater extent than in earlier years. This third edition refers to these three core themes throughout its pages. Nevertheless, the fundamentals remain unchanged, namely:

- the scales used must have known and strong psychometric properties (Chapter 2)
- evidence (both qualitative and quantitative) needs to be ascertained from the most rigorously scientifically designed studies (Chapter 3), taking into account the complexity of the intervention (Campbell *et al*, 2000, 2007; Tansella *et al*, 2006)
- in many outcome studies, symptom and social domains (such as quality of life and employment) need to be assessed concurrently (Chapters 5, 8, 9, 11, 13, 14 and 16)
- scales need to be applicable and relevant to a wide of settings to allow valid international comparisons (Chapter 17)
- an inclusive approach to the whole range of mental disorders is required, so that people are included whose conditions have sometimes been excluded from care, such as personality disorders (Chapter 15).

At the same time, a clear trend is now identifiable not so much to look at mental disorders in terms of their producing chronicity, impairment and severe disability but instead to emphasise the hope of recovery (Chapter 4). Central to this view is the participation of service users in research (Chamberlin, 2005) and a more nuanced approach to potential collaboration between people disclosing experience of mental illness, and

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others, in the development and use of outcome measures (Sweeney *et al*, 2009). In other words, people with direct experience of mental illnesses (both service users and family members) are gradually coming to be seen less as the ‘subjects’ or ‘objects’ of research, and more as those in fact with the greatest depth of knowledge and experience of the conditions. They are therefore in the strongest position to give valid ratings of which treatments and services confer benefit (Chapters 1, 6 and 7). This change of perspective is of fundamental importance (Rose *et al*, 2006).

In a global context, this edition documents the continued and rapid production of new scales and the translation of psychometrically well established scales into new languages (Sartorius & Kuyken, 1994; Thornicroft *et al*, 2003). Even so, the number of effectiveness studies does not distribute equitably across international settings; in particular, few, as yet, have been carried out in low-income countries (Saxena *et al*, 2004; Patel *et al*, 2007; de Jesus *et al*, 2009).

There is another sense in which outcomes are important, namely how far the results of research are used to shape and improve routine clinical practice. This applied end of the research spectrum has been referred to as ‘implementation science’, and is itself at present underdeveloped, under-researched and underfunded (Tansella & Thornicroft, 2009). For example, although many hundreds of papers refer to the creation of clinical guidelines, few studies have explored under what conditions clinicians actually put such guidelines into practice (Madon *et al*, 2007; Proctor *et al*, 2009).

The operational linkages between policy and practice are therefore now being scrutinised as never before, both to identify interventions which are effective and cost-effective, and to judge how to realise behavioural changes on the part of practitioners that lead to better outcomes for people with mental health problems (Chapters 10 and 18).

When the first edition of this book was published in 1996, we wrote that ‘research instruments are the basic tools of health service evaluation’. We would now add that the skilful use of these tools requires, as for artists or craftsmen, a clear eye for design, a steady and relentless focus upon the needs of the consumer, and the skill to realise the creative intent – in this case better mental health (Thornicroft & Tansella, 2009).

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