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Perspective Piece

Reassessing 'recovery' in the light of Mad Studies: a survivor perspective

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Abstract

This Perspective article addresses the issue of recovery in mental health research, policy and practice from a service user/survivor perspective. In doing so, it brings to bear a fundamentally different viewpoint to that which has dominated psychiatric history, one based on lived experience rather than the ideological allegiances of its founders. The article addresses the modern history of Western mental health provision, its over dependence on medicalised individual understandings of wellbeing, the limitations this has imposed and the challenges it has been subjected to. The issue of recovery is examined in its historical context, exploring its strengths and weaknesses. The latter weaknesses have been magnified by the association of recovery by different governments, nationally and internationally, with pressing mental health service users and others experiencing distress into employment; this is often poor quality and unsupported employment. The article puts this in the broader context of a number of values and principles underpinning both the developing psychiatric system survivor movement and the emerging international interest in Mad Studies. In doing so, the article offers a basis for the radical reform of both understandings of madness and mental distress, recognition of their holistic relations and more helpful routes to offering support and engaging with the lived experience and experiential knowledge of mental health service users.

Keywords: Mad studies; public patient involvement; recovery approach; human rights; equity; diversity; lived experience

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Introduction

If there is one Western policy and practice that in the current vernacular demands an urgent 'reset', then I would suggest it is 'mental health'. This also seems to be a global issue. Ever since the European Enlightenment of the eighteenth century, society seems to have been stuck with dominant Western understandings of madness and distress based on the particular narrow interpretations of what counts as science, knowledge and evidence handed down from that distant movement. This has perpetuated a particular medicalised individual model of madness and mental distress which continues to be exported globally, regardless of other understandings and traditions.

I would also argue that this tradition conspicuously fails to connect with the widespread experience of both mental health service users and practitioners. In this discussion, I want to foreground this failed and damaging inheritance and also highlight other understandings and interpretations of the problems people may face with their mental wellbeing and how these may help us both improve that wellbeing and challenge the unhelpful dominance of such past assumptions and ideas.*

I should perhaps also begin with a few caveats. This article is not intended as an attack on what we might for simplicity call the psychiatric system: that developing constellation of learning systems, occupations and professions, structures, services and institutions that have developed over the years. Instead as will emerge, it is based on a *different* paradigm, that of the lived experience of those on the receiving end, rather than those taking the lead in shaping its professional, organisational and knowledge base. This results in different understandings, based on different ideological assumptions, but what we can hopefully say both have in common is an overriding commitment to support the rights, interests and well-being of patients/survivors, their loved ones and communities.

I should also add that it is not being suggested here that all is problematic about mental health provision. I have written elsewhere of my own positive experiences of it (Beresford, 2023). Related research, and certainly my own lived experience, however, does also highlight that many of its strengths follow from the skills and qualities of its workforce, rather than its ideological or organisational basis (Beresford *et al.* 2011).

Of course, the psychiatric system if we may call it such as a shorthand, now includes a wide range of occupations, professions and perspectives, some like social work bringing a much more social orientation to its working. It may be argued that services have become more biopsychosocial in nature as they now involve medical, nursing, psychology, social work and occupational

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therapy – and indeed peer support workers. However, the psychiatric system is still strongly based on a hierarchical model which continues to privilege medicalised individual approaches to explanation and understanding and can result in the primacy of psychiatric professionals. Two breakaway movements from within these professions, critical psychiatry and psychology have highlighted these fractures and inequalities.

The persistence of the dominant paradigm

What is interesting here is not so much the question marks placed over the psychiatric system, but how it has managed for so long to resist the endless intellectual and evidential assaults made on its authority. Thus, the successive critiques and condemnations of anti-psychiatry, critical psychology and psychiatry, radical social work and then most recently and perhaps most significantly, the psychiatric system survivor and Mad Studies movements. All of these have certainly called into question the helpfulness of an explanatory system which can essentially locate the problem within the individual, in biomedical terms and as a corollary to this, over-focuses its 'treatment' responses on individualised pharmacological interventions, compulsion and the restriction of rights.

We are now repeatedly told that 'mental illness' is the same as physical illness and that we should approach both with a similar mindset. Yet the reality is that this is not how policy, practice and analysis seem to work. 'Mental illness' and responses to it are closely associated with stigma, segregation, discrimination, rejection and exclusion. This is as much a political as a policy response. It is not how it is with physical illness. A strong case can be made that mainstream responses to 'mental illness' have developed and improved little over the last half to three-quarters of a century, with the same old songbook of drugs, segregation, institutionalisation and compulsion still in use which would have been familiar to patients and families from the first half of the twentieth century. Yet in contrast, physical health care would be almost unrecognisable to our predecessors, with keyhole and micro surgery, routine operations on foetuses, transplants, robotics, genetic and bio-engineering.

The problems with the paradigm

Yet, this does not seem to have stopped the psychiatric system expanding in influence and impact. Instead, we can see that its diagnostic empire has actually widened, and it has thrived on the individualised, competitive and harsh neoliberal politics that have dominated over the last half century or so. As collective supports have been dismantled in the name of the 'small state' and values of people 'standing on their own two feet' and 'taking responsibility for themselves', so consumerist and psych-based approaches have gained ground in public policy, and increasingly social problems have been framed in individualistic terms, with ever more pathology identified. We only have to look at the front-page furore against disability benefits (including for mental health service users) in the United Kingdom (UK) and beyond to see this writ large (Crerar & Elgot 2025). In informal alliance with neoliberal politics and economics the psychiatric system has extended its influence, authority and dominance, despite its highly qualified track record of achievement.

Yet, as I have said, all this has been happening against the grain of the rising questioning of the psychiatric system, its limited effectiveness for some and its limited ability to innovate compared to the scale of progressive change over a comparable period in physical medicine and health care.

Not only has this questionable model of mental health dominated in societies like the UK, despite its evident limitations, but it has also been exported and imposed on global south countries long subject to the colonising activities of western nations. The latest iteration of this is the so-called global mental health movement (Beresford & Rose, 2023).

Two key developments

Having said all this, two significant developments can be identified in the recent history of Western mental health policy, practice and knowledge development. These can be headlined as the introduction of public patient involvement (PPI) and the 'recovery' movement. Both are international developments. Both have gained high profile and been adopted by UK and other governments. Both have been offered as progressive developments of the existing psychiatric system. Yet we can see that both raise more complex issues and the responses to them have been mixed. Indeed, both can be seen as having both progressive and regressive potential. Given this, what seems important is to examine them more carefully in order to make more sense of them and determine first what problems, if any, they may raise, and then consider perhaps how they may be most helpful. First let's look at what has come to be called PPI or public patient involvement.

Public patient involvement

The mainstream pressure for PPI can be traced back to the political shift to the right signified by New Right and market-driven politics from Mrs Thatcher onwards. Rejecting state intervention as wasteful and inefficient, these opted instead for an approach based on individual responsibility, purchase of service and market-based provision, resting on consumerist ideology. The rhetoric was of extending ideas of customer choice and voice into the public sector and this was associated with new provisions for such consumer involvement in health care and other public services. Significantly an important early site for the development of this approach at least in the UK has been mental health policy and services. While this was framed in terms of involvement, for the most part this was interpreted in consultative and market research terms of finding out the views and preferences of consumers as a basis for policy development, rather than including them in the decision-making process. Thus, this has mostly meant carrying out satisfaction surveys and developing quality standards. It has often been seen as a supermarket model of involvement, rather than one which shifted the locus of control or redistributed power in organisations, policies and services. As a result, it has resulted in accusations of tokenism and frustration that it did not lead to significant changes or improvements in line with the expressed preferences of service users individually or collectively. A major problem with this innovation has been that people expected it to offer much more than it was perhaps intended to achieve. Because the language of consumerist and democratic involvement is essentially the same, what benefits it might have made possible, for example, in terms of improving the fit between services and their users, has often been obscured by resentments that people who got involved were merely being used to legitimise and rubber-stamp pre-existing decisions (Beresford, 2019). To be truthful, more than this was rarely on offer.

Recovery

The same problems of ambiguity can be identified in the idea and practice of recovery, the second of these two major recent developments in mental health policy and practice. It has become a dominant idea in Western mental health policy. There are now 'recovery colleges', a large and rapidly growing recovery literature, recovery courses, leaders, experts, consultants, advocates and research. However, we also know that recovery is a controversial idea. It has gained widespread support from different stakeholders, including mental health commentators, professionals, service users and family carers. But it also has critics among all these constituencies, including this author. Reservations raised are less to do with the essential definition of 'recovery' than with its ideological, material and practical relations. But it is also a concept with great power, because it seems to challenge some longstanding assumptions that problems of mental illness were non-recoverable. No matter that such assumptions have never been as monolithic as may be assumed, this has given it a strong progressive gloss, as though it challenges and is a counter to dominant historic negative views of mental distress. And to reject the idea that people who experience 'mental health problems' should be written off as incurable seems, to say the least, reactionary and unhelpful. But the truth is that recovery is a much complex concept here than its face value would suggest. This is particularly important for two reasons. First is the complicated and variable nature of madness and distress. They can be short-term or long-term, intermittent or one-off difficulties. But unfortunately talking about recovery has come to be taken to mean that people can manage without help, when it may be that very help which enables them to keep going and function to their best. This is the equivalent of suggesting that if a disabled person is managing okay, then all their supports for mobility and communication, for example, their wheelchairs and hearing aids, could be withdrawn. No one would find this defensible. It clearly makes no sense, but in the real world of mental health policy in countries like the UK, withdrawal of service is frequently exactly what recovery is taken to mean. The result is more difficulty, failure, loss of confidence and often of sustaining achievements, contacts and relationships.

Recovery and employment

But there is also perhaps an even bigger problem here. Successive governments, in the UK and beyond, prioritising neoliberal ideology, have placed an increasing emphasis on people being in paid work. This policy has been imposed harshly on disabled people including mental health service users (Pring, 2024). Having a job became a routine part of official definitions of social inclusion and now the concept of recovery has become inseparable from it. It has become a key measure of government definitions of recovery, however inappropriate employment, or the kind of employment that may be available to mental health service users, however else they are able to demonstrate actual improvement and contribution, for example, through voluntary action, education and skill development. Currently the most extreme version yet of this crude coupling has been touted by the UK government, with talk of job advisers being embedded in health services (Bartholomew, 2024). It is difficult to see how such a policy can be seen as in any way helpful as an aspect of mental health policy or practice or in line with any meaningful notion of 'recovery'.

While acknowledging the recognised limitations of using X/ twitter as a mode of collecting data, I asked people what they thought on X/Twitter, as using such social media is something many mental health service users routinely do. Here are a few of the comments I received back – all in similar vein:

I guess the issue is when staff/job centre/DWP are the ones defining 'recovery' and foisting it onto the service user to offramp them . . . rather than the service user creating their own definition (and being given space and time to actually recover.

My view of what 'recovery' means is different to the UK government's view of it because we have different priorities. Even with something physical like arthritis, I recovered in 2017, overdid things, pushed myself too hard, relapsed & now I'm worse than I was before.

Recovery is too tied to being in employment. I struggle to do many things consistently and then my autism makes me less suitable for many jobs. I doubt I could do a suitable full-time job so I will never officially recover.

Discourse about recovery has sadly been tainted by governments tying it to paid work. Indeed, it is difficult to see how dominant discussions of 'recovery' or the overall mental health model onto which these have been grafted offer any positive hope for future mental wellbeing.

A real rethinking of our mental wellbeing and responses to it

The opposite I believe is true of the kind of principles that the international survivors and Mad Studies movements have consistently been highlighting. I would suggest that it is in the light of such principles that both PPI and current approaches to recovery can best be judged and indeed that more generally, they may offer us both a template and a route map for the radical renewal of both the conceptualisation of and responses to our mental and holistic wellbeing.

Mad studies

The key values of the Mad Studies movement include that:

- It rejects a bio-medical model of our 'mental well-being'/mental illness/disorder etc.
- It is based on a rights, social and holistic approach, rather than individualised understandings and approaches.
- It values and gives priority to survivors' lived experience and first-person experiential knowledge.
- It values survivors being able to speak and act for themselves.
- It emphasises the importance of inclusion, treating diversity with equality, decolonisation and challenging the dominance of global north ideas and models and devaluing of indigenous and global south understandings.
- It is survivor-led but not limited to survivors; it is open to all to be involved who accept its principles.
- It is supportive of building broader alliances beyond 'mental health' with other groups committed to the principles on which it is based.
- It builds on collectivist approaches to understanding, organising and making change.
- It is explicitly ideologically and theoretically based (LeFrancois et al., 2013).

A broader agenda for action and change

All this builds on the values and principles of the international psychiatric system survivor movement, which emerged in the 1980s.

These highlight:

- An approach to involvement concerned with the redistribution of power, the achievement of social justice and an effective say in decision-making for people as mental health service users/survivors. This democratic model of involvement (in contrast to PPI's predominantly consumerist model) was intended to ensure that service users' views and actions could have an effective impact on policy, practice and research. It's not just a matter of trawling people's views but listening to and acting on them.
- Recognition of the importance of supporting service users' own initiatives for change, so that the process of involvement effectively starts from the beginning.
- A shift in emphasis in knowledge production, to avoid privileging the 'expert' and professional knowledge of workers and researchers, to seek to give equal value to the lived experience and experiential knowledge following from it of people as service users. This represents a challenge to traditional positivist research values based on objectivity, neutrality and distance and seeks to overcome the inherent discrimination or 'epistemic injustice' of research values which automatically give priority to outside research and expertise.
- Involvement which is primarily concerned with accessing the contribution of people as service users, rather than taking prevailing narratives as its starting point. It seeks to enable service users to develop their own ideas, agendas, priorities and proposals.

Key principles

To do this, it seeks to extend their body of knowledge rather than merely reinforcing existing research and professional knowledge. This means treating such experiential knowledge with equality. If this is to work, then such involvement needs to be inclusive involvement, challenging the numerous exclusions often associated with participatory initiatives (Beresford, 2013). Anything less than this will reinforce prevailing exclusions and only result in a partial picture.

To enable such inclusive involvement, there need to be provisions for access and support for service users, ensuring there are effective ways for them to be encouraged to get involved in processes and organisations and that they have opportunities to develop skills and confidence. Such processes of empowerment are important because they put people in the position to take part – personal empowerment – as a basis for political empowerment – being able to work with others for broader change.They are also a reminder that involvement is a collective as well as an individual activity – there can be group as well as individual self-advocacy; that working together is often key to making change; and that self-organisation – building user-controlled organisations – is an important aspect of effective involvement.

It is also important that as well as aiming for inclusive involvement, agendas should be based on principles of anti-discrimination, challenging the exclusions and discriminations that some groups of people routinely face in their lives and activities. Such discriminations are also linked with inequalities associated with historic colonialism; efforts to decolonise practice, policy, learning and research are also important in challenging and overcoming these.

Building an agenda together

This is not an exhaustive list of values and principles for participatory and co-producing policy and practice. Others will have additional ideas to add. However, what is important in any effort to get beyond the limitations of existing over-medicalised and individualised understandings of mental health and well-being is to support people with direct lived experience to be central to the process of change. This means recognising that many of us may need help to get to the starting point of this journey for change, that it is one that concerns us all, whatever our role, and that it is one which (while it demands change at every level – individual, social and political) crucially starts with a commitment to building trust and equality in roles and relationships. This is the true starting point for us to get to the next level – coproduction.

Acknowledgements. I was originally asked to write this as an editorial after being invited to speak at a conference. Subsequently we ran into difficulties with its publication which the Journal's editor helpfully sought to resolve by suggesting I write it, rebadged as a Perspectives article. I am happy to take up this offer because I believe this issue reflects a much broader one in the analysis and theorisation of what is variously called 'mental illness' and 'madness'. I believe it is helpful to surface such difference and disagreement and the discourse that goes with it as part of a constructive and bridge-building process.

My work over a long period has been concerned with people's participation – in practice, policy, politics, research and knowledge creation. Over this time if I am honest I have experienced exclusion, censorship by peer review and the like – and I know colleagues to whom the same has happened – where their writing has not conformed with ruling ideas and understandings and they have not had the power successfully to challenge this. Over the same time, I have also happily seen the acceptance of many ideas we have advanced which were formerly disputed, particularly in relation to participation, diversity, social inclusion, decolonisation and new approaches to knowledge creation. That's why I welcome this journal's editor's decision to find a way forward for this specific discussion. Thus, we all open ourselves to different thinking, are able to make evidence-based judgements and decisions about it and generally advance the goal we all have – to critique, strengthen understanding and develop the professions and disciplines with which we are concerned. I believe we all learn from and benefit from such processes – and I certainly include myself in this.

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Ethical standards. The author asserts that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008.

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