

Institution: Birkbeck, University of London

Unit of Assessment: 30 Philosophy

Title of case study: The Philosophy of Mental Health Activism

Period when the underpinning research was undertaken: 2013-2020

Period when the claimed impact occurred: 2018-2020

Is this case study continued from a case study submitted in 2014? ${\sf N}$

1. Summary of the impact

Rashed's expert evidence to the Independent Review of the Mental Health Act influenced its outcome by emphasising the importance of cultural competence and bias, creating remedies to the overrepresentation of BAME people detained under the Act. His research has influenced legal practice and guidance through 39 Essex Chambers, a barristers' chambers specialising in health and welfare, which cited Rashed in its *Mental Health Capacity Report*.

Rashed influenced internal government guidance on mental health: Public Health England cited his research as among the most important recent studies on mental health and included his research in its Mental Health Current Awareness Update, signalling his work's significance in effecting mental health treatment and approaches.

Mental health practitioners and their clients have benefited from Rashed's workshops at the Royal College of Psychiatrists; senior practitioners reported benefits and have changed practice. The private practice Psychology Sussex has fully incorporated Rashed's research into its CPD training, benefiting nearly twenty thousand clinical therapy sessions annually.

2. Underpinning research

The claim that 'madness' can be grounds for identity has engendered significant scepticism; for example, mental health problems are associated with distress and disability, and are typically considered to undermine the capacity for identity formation. Mental health problems place marked tension on several concepts such as rationality, agency, self, personhood, and moral and legal responsibility. They lie at the limits of these concepts or outside them altogether. In his research, Rashed, an early career researcher, analyses and addresses these objections and in doing so creates the possibility for ideas from mental health activism to inform clinical thinking and practice. His particular focus is Mad Pride, which began as a grassroots movement composed of people who use mental health services, their allies, and others who experience unusual mental states. The movement advocates for alternative and less stigmatising understandings of mental health conditions.

Rashed's 2019 *Madness and the Demand for Recognition* is the first philosophical monograph that addresses these issues [REF1]. It offers a comprehensive assessment of the claim that madness can be grounds for identity, examines the normative force of the demand for recognition of Mad identity, and proposes a way forward for a positive social response to Mad Pride. The journal *Sozialpsychiatrische Informationen* described *Madness and the Demand for Recognition* as "the first book that, in terms of the theory of recognition, is devoted to the central question of social psychiatry: how - outside of a medical-psychiatric framework - can we deal with demands for social and cultural recognition by people with psychiatric experience".

In 'The Identity of Psychiatry and the Challenge of Mad Activism' [REF2], Rashed focuses on the clinical encounter. He introduces a number of concepts that can render the encounter amenable to working with ideas from Mad Pride. His paper 'In Defence of Madness' focuses on mental health and the social model of disability [REF3]. It demonstrates the application of the concept of reasonable adjustments to psychiatric phenomena. This paper was selected by Oxford University Press for the 'Best of 2018' Philosophy list and has regularly featured in the top 5 most read articles in the Journal of Medicine and Philosophy (<u>https://academic.oup.com/jmp</u>). It has received praise from a distinguished Professor of Mental Health Studies, as "one of the best things I've read on the subject. I really like the way you explore intelligibility alongside the kinds of narrative we put forward to create meaningfulness and the assumptions underpinning them – and the implication that we might need to change fundamental ideas about humanity [this is] very helpful" (1). In 'The Critique of Psychiatry' [REF4], he introduces psychiatrists to recent philosophical and activist literature in mental health. The paper was published in the BJPsych



Bulletin, distributed bimonthly to all members of the Royal College of Psychiatry, approximately 16,000 doctors worldwide.

In papers [REF5] and [REF6], Rashed develops aspects of the foundations of his more recent work. He examines a range of psychiatric concepts and practices with regards to their ability to define more clearly the boundaries of illness. With Rachel Bingham, in 2014, he co-wrote 'Can Psychiatry Distinguish Social Deviance from Mental Disorder?' [REF5]. They argue that the concepts of psychiatry are unable to distinguish socially constituted forms of distress from intrinsic distress. In some clinical encounters, social action and not individual treatment ought to be the primary level of intervention. In 'Culture, Salience and Psychiatric Diagnosis', Rashed examines the concept of cultural congruence as it applies to diagnosis across cultures [REF6]. He develops a framework for distinguishing culturally normative behaviours and experiences from mental illness.

3. References to the research

(REF1) Rashed, Mohammed Abouelleil, *Madness and the Demand for Recognition: A Philosophical Inquiry into Identity and Mental Health Activism.* Oxford University Press, 2019. (REF2) Rashed, Mohammed Abouelleil, The Identity of Psychiatry and the Challenge of Mad Activism: Rethinking the Clinical Encounter, *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, Volume 45, Issue 6, December 2020, Pages 598–622. DOI: <u>https://doi.org/10.1093/jmp/jhaa009</u>

(REF3) Rashed, Mohammed Abouelleil, In Defence of Madness: The Problem of Disability. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, Volume 44, Issue 2, April 2019, Pages 150–174. DOI: https://doi.org/10.1093/jmp/jhy016

(REF4) Rashed, Mohammed Abouelleil, The Critique of Psychiatry as we Enter the Third Decade of the 21st Century, *BJPsych Bulletin*, 44(6), 236-238. DOI:

https://doi.org/10.1192/bjb.2020.10

(REF5) Rashed, Mohammed Abouelleil, and Bingham, Rachel, Can Psychiatry Distinguish Social Deviance from Mental Disorder? *Philosophy, Psychiatry, & Psychology*, 21(3), February 2020, 243–255 (2014). DOI: <u>https://doi.org/10.1353/ppp.2014.0043</u>

(REF6) Rashed, Mohammed Abouelleil, Culture, Salience and Psychiatric Diagnosis: Exploring the Concept of Cultural Congruence and its Practical Application. *Philosophy, Ethics, and Humanities in Medicine*, 8, 5, 2013. DOI: <u>https://doi.org/10.1186/1747-5341-8-5</u>

4. Details of the impact

Each year, around 1 in 4 people will suffer from a mental health problem. In the UK alone, this represents approximately 16,700,000 people, and it is on the rise: between 1993 and 2014, the number of people with common mental health problems rose by 20%

(https://webarchive.nationalarchives.gov.uk/20180328140249/http://digital.nhs.uk/catalogue/PUB 21748). Meanwhile, BAME people are more likely to be diagnosed with a mental health disorder, are more likely to be detained under the Mental Health Act, and are less likely to receive treatment if in the criminal justice system.

Mad Pride began in the 1990s as a grass-roots campaign, aiming to resist stigma and to bring about change in societal views of mental health conditions. Mad Pride has been particularly controversial, given its rejection of the language of mental illness and its presentation of 'madness' as grounds for identity. Rashed's research provided the evidence base to allow ideas from Mad Pride to productively inform clinical thinking and practice.

Mental Health Act Review

In 2018, Rashed was asked to provide expert evidence to the Independent Review of the Mental Health Act at the Department of Health. This was the first review of the Mental Health Act in 10 years, culminating in a final report (2). Key concerns driving the review included the rising levels of coercion within mental health services, and in finding the complex balance between respecting a person's autonomy and the duty of a civilised State to protect the vulnerable (2). Rashed's research examines this concern and can be read as an attempt to redress the balance



towards patient autonomy (REF1, REF3, REF6). Rashed gave specific advice around cultural competence, cultural bias, and cultural and historic trauma (2).

The evidence that Rashed provided was incorporated into the report's key findings as follows:

Cultural Competence

Rashed emphasised (2) the importance of not mistaking cultural beliefs and experiences for mental disorder and the need to seek cultural congruence, i.e. seeking harmony between the individual service user and their presumed cultural context. Moreover, Rashed pointed out that mental health disorder diagnoses happen when patients deviate from accepted epistemic, ethical or social norms. Thus, disorder diagnoses are more likely when clinicians and service users come from different cultural backgrounds, leading to a breakdown in cultural congruence.

The report consistently emphasises the need for clinicians and other service-providers to develop cultural competence (2), drawing on Rashed's evidence when it states that a lack of cultural congruence can lead to misdiagnoses and that such misdiagnoses lead to an overrepresentation of ethnic minorities in detention. Furthermore, the report recognised that despite existing regulations, advocacy to meet the needs of diverse communities is not always available, again drawing on Rashed's advice: 'Where this is not happening,' the report recommends, 'commissioners should be held to account [...] via the Organisational Competency Framework' (2). Additionally, drawing on Rashed's evidence, the report notes an 'insufficient' focus on training for NHS staff on cultural competency, noting that a lack of competency poses a significant barrier to appropriate treatment for patients with protected characteristics (i.e. those covered by the Equality Act 2010). It recommends, 'as a minimum' that government ensure that regulations and standards governing key decision-making professions 'are relevant and fit for purpose'. This, again, reflects Rashed's evidence to the panel (2).

Cultural Awareness

Recommendations that drew directly on Rashed's evidence in relation to cultural awareness include:

- Ensuring the provision of culturally-appropriate advocacy services (including Independent Mental Health Advocates) for people of ethnic minority backgrounds

- Amend the Code of Practice to reinforce the [...] considerations of cultural needs and build on [patients'] own knowledge and experience of their mental illness

In addition, the report dedicates specific segments to "recognising individual and cultural needs" and "culturally-appropriate advocacy". It notes that "the provision of culturally-appropriate advocacy is key to reducing additional stresses and anxieties that could exacerbate a patient's mental condition, as well as to support speedier recovery". Culturally-appropriate advocacy will "help reduce the likelihood of people experiencing mental health services as abusive and that disenfranchised patients have their views heard, recorded and considered, and that dignity is upheld".

The white paper to reform the Mental Health Act has been delayed, initially due to the general election and then the Covid crisis. In the meantime, the Care Quality Commission have published their <u>Monitoring the Mental Health Act in 2019/20</u> report (3), which highlights the need for greater access to advocacy services, one of the key recommendations put forward by the Independent Review of the Mental Health Act (2).

Legal practice

39 Essex Chambers is "widely regarded as having the biggest and best health and welfare team in London or anywhere else". Their monthly *Mental Health Capacity Report* is a training resource that supports other Chambers to interpret and understand mental health issues. Their April 2019 *Report* cites [REF1] as raising questions concerning the "validity of psychiatry as a response to 'madness and distress'", in the context of the UN Convention on the Rights of Persons with Disability (4). Using high profile cases, such as Rachel Johnston (a severely disabled woman who died in 2019 after her teeth were removed without her consent or her mother's knowledge (5), they highlight the ongoing debate over the capacity of people with mental health disabilities to determine their own treatment. Rashed has argued for more autonomy for people with mental



health problems, both in terms of decisions concerning their care as well as the broader understanding and meaning of these problems. The following month, the Chambers cited Rashed again [REF3], this time in the 'Research Corner' section of their newsletter, which highlights recent research articles likely to be of interest to practitioners (6). This edition of the *Report* highlights a case heard in which a woman on the autistic spectrum and with a severe learning disability was given a hysterectomy to alleviate the profound distress that her menstrual cycle caused her. This was a case about autonomy, capacity, and the best interests of individuals, and Rashed's article on mental health and the social model of disability [REF3] was recommended reading in this context.

Public Health Guidance

Rashed's work has influenced internal government guidance on mental health. Public Health England's (PHE) Knowledge and Library Services provides "knowledge, library and evidence services to PHE" in order to "protect and improve the nation's health and wellbeing, and reduce inequalities, by providing and mobilising the best available evidence for public health". As part of their remit the service regularly publishes a *Mental Health Current Awareness Update (MHCAU)*, providing PHE with "the latest, best evidence about mental health, to help (PHE staff) make informed decisions" that affect healthcare provision at the national level, and provides a curated, up to date reading list of the best, most valuable research on mental health. The June 2020 *MHCAU* (7) cites [REF1] as among the most important recent studies.

Clinical Practice

In 2019, Rashed conducted workshops at the Royal College of Psychiatry. The workshops brought together psychiatrists and other mental health professionals, service-users, and third-sector workers. That is a significant achievement in itself given the historical resistance that these groups often have to such interventions, and testament to Rashed's standing among clinicians, professionals and service users. The workshops introduced practitioners and other stakeholders to key concepts conducive to working with Mad Pride in clinical practice. They were targeted specifically at senior practitioners with specialist expertise, increasing the reach across their institutions and across the sector. The workshops' approach drew on a mixture of focus groups and teaching/training methods, maximising the impacts by developing concepts and drawing out participants' understandings and insights.

Many senior practitioners reported a range of benefits and changed practice as a result of the workshops:

- "I will develop this distinction with my trainees as part of reflective practice" (NHS consultant clinical psychologist).

- "This [...] has helped me think in new ways about the clinical encounter and mental health" (senior academic in practice-based medical humanities and advisor to the Royal College of Psychiatry).

- The workshop "made me aware of the multi-faceted nature of reconciliation and forgiveness [...] my research could look at this theme with regards to patient groups" (consultant psychiatrist at a community mental health team).

- "the discussion of concepts [was] useful in clarifying arguments in my work" (consultant psychiatrist working in policy and public health) (8).

Rashed's research has directly and fundamentally affected private practice in the sector, too. The Clinical Director and chartered psychologist of independent psychological healthcare practice Psychology Sussex states that Rashed's research has been "invaluable in the field of mental health, especially with regard to broadening the perspective on the experience of 'madness', and implications for mental health practice" (9). Rashed's critique on the categorisation of individuals and informative embrace of lived experience has been fully incorporated into the practice's in-house CPD training, positively influencing therapeutic interventions with clients (9). This training has been delivered to the 40-strong team, who each conduct between 10 and 20 therapy sessions per week, equating to approximately 19,200 sessions per year conducted with an average of 500 service users. The Clinical Director subsequently invited Rashed to speak at Soteria Brighton, the local branch of a global network of practitioners. Around 100 practitioners and lived-experience users will attend the future



session and it will be uploaded on to the global Soteria Network, accessible to anyone affiliated with Soteria. The Brighton branch alone reaches around 500 people (practitioners and service users) (9).

Rashed's work has further influenced the practice of clinical psychologists globally. A clinical psychologist and researcher from Frankfurt, Germany praised [REF1] as "the first substantial book in the field" and "very inspiring [...] it's now possible to discuss the implications of the concept [of recognition] and its potentials and limits [in mental health] based on your work".

Charities and other public organisations

Pink Sky Thinking, a Mad Studies reading group of lived experience practitioners and consultants, service-users, and activists (<u>https://www.pinkskythinking.com/post/mad-studies-david-tackles-madness-the-demand-for-recognition</u>) used [REF1] to encourage "people to use different language, and to participate [in activism] differently" (8, 10). A review by a lived experience researcher and mental health activist has also noted that [REF1] "amplifies the value of Mad Pride efforts to bring about societal transformation, and may offer us some theoretical anchors [...] to bolster our activities" (10). The book is also cited as a resource by mental health activists' website, *Radical Abolitionist* (10).

In August 2018, the non-profit Mad in America invited Rashed to deliver a webinar on his research to mental health practitioners and service-users (10). The forty-five US-based participants included psychiatrists, psychologists, therapists, activists, and service-users, reporting that the webinar created "new learning" and inspired users to understand Mad narratives as "part of clinical encounters".

5. Sources to corroborate the impact

1) Email: Professor of Mental Health Studies

2) Modernising the Mental Health Act: Increasing choice, reducing compulsion. Final report of the Independent Review of the Mental Health Act 1983 (December 2018); Email correspondence with Policy Manager, Mental Health, Department of Health & Social Care; Rashed's evidence to the Mental Health Act Panel; Independent Review of the Mental Health Act 1983 <u>https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act</u>
3) Monitoring the Mental Health Act in 2019/20 Report, Care Quality Commission (2020)
4) Mental Capacity Report: The Wider Context, 39 Essex Chambers (April 2019), 93.
5) BBC News 'They took her teeth without telling me' (January 2019)
https://www.bbc.co.uk/news/uk-england-46608205
6) Mental Capacity Report, 39 Essex Chambers (May 2019), 94.
7) Mental Health Current Awareness Update, Public Health England (June 2020)
8) Workshop feedback and testimonials
9) Testimonial: Psychology Sussex

10) Madness and the Demand for Recognition:

i) *Pink Sky Thinking* Blog: 'Mad Studies: David tackles "Madness & The Demand for Recognition" <u>https://www.pinkskythinking.com/post/mad-studies-david-tackles-madness-the-demand-for-recognition</u>

ii) Book Review: 'Madness and the demand for recognition: a philosophical inquiry into identity and mental health activism'

iii) Radical Abolitionist, '28 Ways to Make the World Less Hostile to Mad,

Neurodivergent, and Psychiatrically Disabled People' <u>https://radicalabolitionist.org/2019-</u>2-15-26-ways-to-make-the-world-less-hostile-to-mad-neurodivergent-and-psychiatricallydisabled-people/

iv) Mad Studies: An Introduction to Philosophical, Social, and Cultural Perspectives on Madness <u>https://education.madinamerica.com/p/mad-studies</u>