Kent Academic Repository

Khan, Nagina (2021) *What Is 'Really' Required To Incorporate The User Narrative In The Changing Health Systems?* . Recovery in the Bin Internet publication.

Downloaded from

https://kar.kent.ac.uk/111396/ The University of Kent's Academic Repository KAR

The version of record is available from

https://recoveryinthebin.org/2020/04/14/what-is-really-required-to-incorporate-the-user-narrative-in-the-c

This document version

Publisher pdf

DOI for this version

Licence for this version

CC BY-NC-ND (Attribution-NonCommercial-NoDerivatives)

Additional information

Recovery in the Bin blog article

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in ***Title of Journal*** , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

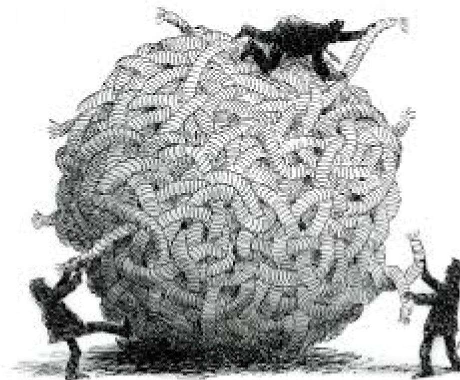
Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Recovery in the Bin

A critical theorist and activist collective.

What Is ‘Really’ Required To Incorporate The User Narrative In The Changing Health Systems?



by Nagina Khan

The concept of recovery emerged from the service user movements in the 1970s, most notably in Anglo-Saxon countries, challenging traditional medical approaches to treating people with mental illness and how services for these individuals are organised and delivered (1).

Over the last decade, the recovery movement has attracted widespread interest and as a result, has become part of broader change and improvement processes across mental health systems in many industrialized countries (1). However, recent debates suggest that such narratives are often used by mental health and educational systems to promote their own agendas (2). In this context, user narratives are no longer considered a transformative act of co-production or resistance and they are a commodity servicing primarily the interests of these systems (2).

Co-production has become a way of talking about service-user participation in mental health services (3). Co-production relies on a seemingly *‘simple definition—people who use services collaborate in the production of services’* (4) and is generally presented as a ‘valuable element of quality and service improvement’ (5). However, the concept of co-production is also known for its ‘excessive elasticity, evident in the various ways in which it has been defined and interpreted’ (4). Not surprisingly, co-production has been described as a paradoxical space (6), with a potential to both reinforce and transform existing practices and systems (7).

Needham and Carr (2009) provided a helpful distinction between three levels of co-production, however Sapouna (2020) argues that the contribution of user-narratives can only be meaningful in the context of pursuing the third level of transformative co-production as described by Needham and Carr (2);

At its most effective, co-production can be transformative, requiring a relocation of power and control, through the development of new user-led mechanisms of planning, delivery, management and governance. It is important to be aware of these levels when claims are made about co-production in professional education(4).

In that sense, transformative user narratives have the power to become a *‘gap-mending strategy’* between expert and experiential knowledge as well as to disrupt dominant narratives of professional knowledge and expertise (7). This requires professionals to shift from a tradition of paternalistic attitudes of helping or being the expert, to working in meaningful alliances and working to re change;

● The new individual pathology approach, and focusing on individual responsibility to recover whilst excluding a consideration of contextual factors

● Privileging certain types of knowledge through narratives that are considered ‘inspirational’ and/or ‘insightful’ (celebrity status), at the expense of other (e.g. incoherent and overwhelming) expressions of distress

● Overlooking the diversity of narratives constituting people’s experience

● A co-production process encouraging compliance with, rather than transformation of, mental health systems (2).

What can the user narrative offer?

The value of user-narratives is well documented, highlighting the contribution of service-user involvement (SUI) to both the micro-level of practice skills and the macro-level of transforming current practice and culture (2). The user narratives of psychiatric survival have been central in organising resistance toward dominant construc-

tions of 'mental illness' and user narratives have also created spaces for co-production with a transformative potential, as traditionally silenced voices can be heard and affirmed (2).

Equally, personal authentications and accounts can enable health and social care professionals to cultivate an understanding into the experiences of distress, of being at the receiving end of services (8) of feeling trapped, not listened to (9), promoting a dialogue (10) and therefore affect professionals' ability to be more empathetic. User narratives, and SUI have been found to facilitate communication, partnership and advocacy skills (11) to reduce stigmatising attitudes (12) to enable practitioners to be more conscious of and reflective on the implications of their practice (13).

The changing climate of health systems and mental health services

Ideally, at the core of this undertaking is the shift from services based on the clinical meaning of recovery (i.e., treatment and symptom reduction as manifested by clinical assessment tools such as the PHQ-9) to recovery as defined by the service user's view of what is needed or desirable in the care s/he is encountering to help him/her resume a meaningful life and valued roles (1).

This shift is seen in the elements of the Five Year Forward View (14) most relevant to the delivery of primary care are:

· *Holistic care* – promoting care that considers multiple morbidity and the social context of the patient

· *Integrated care* – promoting seamless care between different types of care i.e. primary, secondary, mental health and social

· *Patient-centred care* – promoting patient self-care and informed choice

· *Primary prevention* – promoting prevention of disease in healthy people.

In 2016 the Shared View of Quality was published (15) and set out the broad areas of quality that would again support high-quality person centred care for all, now and into the future (15).

Yet, person-centredness is often directed as the counter-narrative to medicalisation, it argues for a critical and reflexive standpoint that considers what happens though the inclusion and use of person-centred narratives and in particular what may be lost in this pursuit of 'voice'(16). The current policy emphasis on 'voice' apprehends the discourse of activism colluding 'in this shift toward individualism, albeit under the guise of participation, collaboration and co-production'(2). This is not an argument against

inclusion, it is rather a call to problematise how 'inclusion unfolds for survivors when suddenly invited to work for systems that have long been sites of systemic discrimination' (7).

In the UK, the NHS Long Term Plan is also mandating 'integrated care systems' (ICSs) to develop and deliver locally relevant 5-year plans (17). Integrated care is proposed as a more efficient client-oriented health model, building services around local populations (18). However there is concern that mental health has not been sufficiently considered in ICSs and integrating organisations need frameworks and tools to describe their integration model – and how it will be evaluated (18). It is further suggested that engaging not only staff but also patients is essential to the process and a necessary starting point for developing methodologies to evaluate organisational changes and outcomes (18).

Hence, patient centredness needs to be explored not only in the context of recovery but service development needs to be aware that they might inadvertently end up perpetuating patterns of knowledge exclusion by privileging certain narratives over others. The relationship between the narrator and the audience is important here and if the audience decides on the value of narratives, this value is no longer embedded in the power of the story, rather, it lies in the perception of the audience (2). As a result, the *'Recovery Narrative can, like other narratives, also silence and exclude, by privileging and valuing certain kinds of reasoning and knowledge'* (19). With narratives becoming increasingly mainstreamed in mental health systems and social networking sites, offering celebrity status on social media, it is important that services recognizes the critical voices as essential components of transforming and humanising mental health services (2).

Reconciliation of the broader political implications and validating user-generated knowledge

Tracy et al., (2019) report that details on integrated care systems are intentionally non-prescriptive, however they encourage localism and adapting resources to community needs and such there have been few examples incorporating mental health (18). The Royal College of Psychiatrists and the King's Fund noting such opportunities have not yet been maximised (20); so it may be the precise time for valuing user-generated knowledge and influencing the direction of service change, which may reinforce health and social care service to rethink traditional assumptions about credibility and legitimacy of knowledge formation (21)and incorporating unsettling questions, for example dealing with people whose value systems are challenging our own and people with whom we struggle to empathize or engage with (2). So as to develop services where co-production is primarily framed in a helpful manner supported by a model of service delivery and management, rather than an approach challenging power structures and transforming services then by exploring ways of being with complexity, am-

biguity and confusion; by recognising silenced, chaotic stories, and by challenging systemic injustice (2). Now might be the time for services to re-align with person orientation and person involvement (22), which are some of the guiding principles of recovery oriented practice (1). Instead of voyeuristic approach to narratives and their potential reduction to a tick box in the management of mental health and educational institutions (2). So that the narrator is actively claiming power (23) in the contexts where their story is shared. Woods et al. (2019) argue, the political effects of narratives are 'only as benign as the context in which they are materialised, will allow' (24). For that reason, an awareness of power relations in the context where narratives are shared, heard and valued is pivotal to change (2). This could prove to be a significant challenge to the mental health services and the current marketised culture (25).

Nagina Khan, Ph.D, PGCert, BHSc Twitter: DrKhan_do

References

1. Pincus HA, Spaeth-Rublee B, Sara G, Goldner EM, Prince PN, Ramanuj P, et al. A review of mental health recovery programs in selected industrialized countries. Int J Ment Heal Syst. 2016;10:73–83.

2. Sapouna L. Service-user narratives in social work education; Co-production or co-option? Soc Work Educ. 2020;

3. Gillard S, Simons L, Turner K, Lucock M, Edwards C. Patient and public involvement in the coproduction of knowledge: Reflection on the analysis of qualitative data in a mental health study. Qual Health Res. 2012;22(8):1126–37.

4. Needham C, Mary Q, Carr S. Emerging evidence base for adult social care transformation [Internet]. Social Care Institute of Excellence. London: Research Briefing 31, Social Cers Institute for Excellence; 2009. Available from: http://www.scie.org.uk/publications/briefings/files/briefing31.pdf

5. National Service Executive. Co-Production in Practice Guidance Document. 2018.

6. Poursanidou D. Critical reflections on paradoxes and unsettling relations in the politics of "co-production" in university-based mental health research. In: Ryan SC& P, editor. Insider, outsider, impostor? Perspectives of mental health service user and survivor researchers and teachers on co-production in academia. London: Middlesex University; 2016.

7. Voronka J. Researching the Politics of Inclusion. Vis Passion Action [Internet]. 2016;2018(21/05/2018). Available from: https://radssite.wordpress.com/tag/inclusion/

8. Fox J. Being a service user and a social work academic: balancing expert identities. Soc Work Educ. 2016;35(8):960–9.

9. Hughes M. What difference does it make? Findings of an impact study of service user and carer involvement on social work students’ subsequent practice. Soc Work Educ. 2017;36(2):203–16.

10. Sen R, McClelland N, Jowett B. Belonging to the library: humanising the space for social work education. Soc Work Educ. 2016;35(8):892–904.

11. Duffy J. Looking out from the middle: User involvement in health and social care in Northern Ireland. London: Social Care Institute for Excellence; 2008.

12. Cabiati E, Raineri ML. Learning from service users’ involvement: a research about changing stigmatizing attitudes in social work students. Soc Work Educ. 2016;35(8):982–96.

13. Higgins A, Maguire G, Watts M, Creaner M, Mccann E, Rani S, et al. Service user involvement in mental health practitioner education in Ireland. J Psychiatr Ment Health Nurs. 2011;18(6):519–25.

14. NHS. Five Year Forward View. Https://Www.England.Nhs.Uk/. NHS England; 2014.

15. Field S, Keogh B, Leng G, May R, Mclean K, Reid W. The National Quality Board.

16. Pascal J, Sagan O. Cocreation or collusion: The dark side of consumer narrative in qualitative health research. Illn Cris Loss. 2018;26(4):251–69.

17. NHS. The NHS Long Term Plan https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/ [Internet]. 2009 [cited 2019 Feb 12]. Available from: http://www.longtermplan.nhs.uk

18. Tracy DK, Hanson K, Brown T, James AJB, Paulsen H, Mulliez Z, et al. Integrated care in mental health: Next steps after the NHS Long Term Plan. Vol. 214, British Journal of Psychiatry. Cambridge University Press; 2019. p. 315–7.

19. Fitzpatrick SJ. Ethical and political implications of the turn to stories in suicide prevention. Philos Psychiatry Psychol. 2016;23(3–4):265–76.

20. Naylor C, Taggart H, Charles A. Mental health and new models of care. The King’s Fund and the Royal College of Psychiatrists; 2017.

21. Videmšek P. Expert by experience research as grounding for social work education. Soc Work Educ. 2017;36(2):172–87.

22. Valderas JM, Gangannagaripalli J, Nolte E, Boyd CM, Roland M, Sarria-Santamera A, et al. Quality of care assessment for people with multimorbidity. J Intern Med [Internet]. 2019 Feb 5 [cited 2020 Mar 25];285(3):289–300. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1111/joim.12881

23. Brosnan L. Service-User Involvement in Irish Mental Health Services: A Sociological Analysis of Inherent Tensions for Service-Users, Service-Providers and Social Movement Actors. Vol. PhD, Department of Sociology. University of Limerick; 2013.

24. Woods A, Hart A, Spandler H. The Recovery Narrative: Politics and Possibilities of a Genre. Cult Med Psychiatry. 2019;(1–27).

25. Rooney JM, Unwin PF, Osborne N. Gaining by giving? Peer research into service user and carer perceptions of inclusivity in Higher Education. Soc Work Educ. 2016;35(8):945–59.

PUBLISHED BY

recoveryinthebin
A critical theorist and activist collective. View all posts by recoveryinthebin →

April 14, 2020 recoveryinthebin Academic Writing Academic Writing