Subjectivity, Citizenship and Mental Health: UK Service User Perspectives

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In a viral 2009 TED Talk entitled 'The danger of a single story', Nigerian feminist author Chimamanda Ngozi Adichie said, 'How [stories] are told, who tells them, when they're told, how many stories are told, are really dependent on power . . . Power is the ability not just to tell the story of another person but to make it the definitive story of that person.'[1]

Introduction

The focus of this chapter is the impact that UK mental health service users/survivors have made on mental health policy and practice in the period covered by this book through their movement and survivor-led organisations. We write as part of this movement, which we believe probably represents the most significant development in this field and therefore one that demands careful and serious examination, particularly in its broader social, political, policy, cultural and economic contexts. It is our aim to develop that discussion and reflect on the ideas of subjectivity and citizenship as pertaining to this social history more broadly.

Training, Mental Health Services and Diversity

How can one chapter tell a story as diverse and multifaceted as our history? At the same time, it has been invisible to most educators of past generations of psychiatrists as we are aware from teaching students over the past decades. While painfully aware of our privilege as highly educated white, Jewish in the case of Peter, survivors of encounters with psychiatry, we have been participants and observers of the matters of which we write and seek to offer an overview of the history of the survivor movement in the UK up to the 2010. This signposts to other writers who can fill in the gaps for future scholarship and research.[2]

It is imperative that this narrative of our movement's struggles for subjectivity and citizenship is brought to the attention of future psychiatry students and trainees. They can get a foretaste for further encounters with the vibrant, dynamic and diverse layers of activism, resistance and collaboration by those activists and survivor/Mad scholars who demanded recognition for our rights, dignity and citizenship. We in our movements have variously been labelled mental patients and service users and claim our own designations as survivors and Mad scholars. Our narrative is necessarily partial, in that space will never permit a complete and definitive account of the diverse experiences, often glossed over in a homogenising simplification and omission of the underlying tensions, complexities and compromises evident over a period of rapid flourishing of activism and scholarship.

Another reason the opportunity to contribute this chapter is very welcome is because it allows us to point out an implementation gap in mental health services. As stated, we know

generations of psychiatrists have not been educated about the activism and achievements within the user/survivor movements which left many practitioners ignorant of the autonomy and agency achieved over the past fifty years. The implementation gap arising from delays in research-based evidence filtering down to practice, plus systemic hurdles involved in changing academic course content, means that it may take years for new knowledge being developed within the user/survivor social movement activist and research endeavours to be accepted as legitimate perspectives. This is exemplified by experience delivering seminars to medical students during their psychiatric training, where my (LB) input on survivor research consisted of two-hour sessions on an elective module. When asked, the students could not speak about what the survivor-developed recovery concepts meant despite being two years into their medical studies already. These are the clinical leaders of the future. Hopefully, inclusion of a brief account of this activity in a significant social history of psychiatry will help future generations of psychiatrists be more aware of what survivor epistemology and tacit knowledge have contributed to our understandings of mental distress and madness.

We aim to introduce readers to the diversity of both activism and experiences within our heterogenous communities, including the silenced voices of BAME, LGBT and indeed women's specific experiences, particularly around motherhood. Very legitimate criticisms of both external and internal historical accounts highlight a homogenising narrative, which has presented accounts from a white, straight and able-bodied perspective. External academic accounts of the user movement have been challenged by the Survivor History Group as distorting and misrepresenting the agency of the service user movement.[3] Internally, the exclusion of the BAME communities' perspectives has been challenged recently by several writers, including Faulkner and Kalathil and Kalathil and Jones.[4] Carr has highlighted the heteronormativity of the user movement.[5] These are the internal reflections of a mature social movement which has developed historically across decades of struggles outlined in the section that follows. We aim also through this work to begin to introduce how the writers and activists in our movement have understood and addressed issues of subjectivity and citizenship.

Social History of the User/Survivor Movement

There is often talk in the UK about ensuring parity between physical and mental health services. This often relates to the funding of mental health services which has increasingly fallen behind that for physical health.[6] Perhaps more revealing are the differences in progress of these two branches of medicine within the National Health Service (NHS) made over this period. Thus, in physical medicine we have seen enormous innovation; the development of heart and other transplants, operations on foetuses, keyhole surgery, joint replacements, massively extended survival rates for many cancers, robotics used in surgery, greatly improved pain control, new diabetes treatments, drug drivers and so on – an almost endless list.

It looks like a very different story in mental health, where patients fifty years apart worryingly could expect little changed treatment. This includes a continuing emphasis on compulsion and restraint;[7] use of electroconvulsive therapy (ECT), despite its evidenced failings;[8] and the ongoing use of drugs like Largactil (chlorpromazine), with well-documented damaging effects like tardive dyskinesia.[9] The psychiatric system is still over-reliant on drug treatments. Psychiatric innovations like 'second-generation

antipsychotics' have brought their own problems, including serious 'side' effects and their widespread and problematic use 'off-label' for groups they were not intended for, notably older people with dementia.[10] It has been estimated that a quarter of a million people are dependent on benzodiazepine and related minor tranquillisers, although it has long been known these should only be prescribed for very short periods of time.[11] The 'talking treatments' service users have long called for have been institutionalised to six sessions of cognitive behavioural therapy (CBT) through the IAPT (Improving Access to Psychological Therapy) programme; and such interventions have increasingly been directed at getting mental health service users into paid work, regardless of the nature and quality of such employment or of how helpful it is likely to be for their mental well-being.

Admittedly after massive delays, the grim Victorian 'lunatic asylums' are now largely gone, although some of their intimidating premises still serve as sites for 'treatment'. As other contributors in this book have pointed out, in 1961 Enoch Powell as health minister gave his famous 'Water Tower speech' promising to get rid of them. It was not until the Act of 1990 and the switch to 'community care' that this really happened and then, because the new policy was implemented so poorly, mental health service users, left without adequate help or support, were again stigmatised as 'dangerous' and a threat to 'the public' (see also Chapters 27 and 28).[12]

The lack of progression in the modern psychiatric system and its association with control, abuse and institutionalisation in the 1960s gave impetus to the development of a mental health service user/survivor movement in the UK.[13] While related 'mad person' protests and activism have been identified from the seventeenth century, Peter Campbell, a founding survivor activist, dated the modern UK survivor movement, which has grown on an unprecedented scale, to the mid-1980s, tracing its origins to earlier mental patient groups from the 1970s and acknowledging the help it received from progressive mental health professionals.[14]

The UK mental health service users/survivor movement can be seen as one of the 'new social movements' (NSMs) emerging globally in the second half of the twentieth century, largely based on shared identity and common experiences of oppression – thus the black civil rights, women's, LGBTQ and grey power movements. Certainly, welfare state user movements like those of survivors and disabled people highlighted their links and overlaps with these NSMs.[15] The UK disabled people's movement was in some ways a separatist one, arguing for different kinds of support to that which had been provided and developing its own underpinning model or theory – the social model of disability and related philosophy for change of 'independent living'.[16] The same separatist drive and radically different philosophy does not seem to have been true of the mental health/survivors' movement. The many groups and user organisations that emerged often operated *within* the psychiatric system, its services and related voluntary organisations and were sometimes directly linked with and funded by the services. While the movement did not have the same kind of distinct philosophical basis or perhaps independence as the disabled people's movement, nonetheless it has highlighted a number of common principles that have endured:

- The lives of mental health service users are of equal value to those of others.
- Mental health service users have a right to speak for themselves.
- There is a need to provide non-medicalised services and support.
- Service users' first-hand experience should be valued.

- Discrimination against people with experience of using mental health services must end.[17]

The emergence of the survivor movement, like other service user movements, was also facilitated by the political shift to the right from the late 1970s which was associated with both a renewed emphasis on the market and devaluing of the state and a growing government rhetoric for consumer rights in public services. While this did not necessarily chime with service users' calls for more say and empowerment, it opened doors to them and heralded a new stage in the broader interest in democratisation and public/user participation. Key stages in this history vary from country to country but include the following:

- Working for universal suffrage in representative democracy and the achievement of social rights, like the right to decent housing, education and health, from the late nineteenth to mid-twentieth century.
- Provisions for participatory democracy and community development, associated with the 1960s and 1970s.
- Specific provisions for participation in health and social care, from the1980s through to the first decade of the twenty-first century.
- State reaction and service user–led renewal as conflicts and competing agendas become more explicit, from 2010 onwards.[18]

While mental health service users/survivors were organising and campaigning before the 1980s, from then onwards their activities mushroomed in scale, visibility, impact and effectiveness.[19] Local and national survivor-led organisations were established. International links were developed. There were organisations that focused on particular issues, like the Hearing Voices Network, as well as some that linked with and included other groups of service users, beyond mental health service users/survivors. These included, for example, the Wiltshire and Swindon Users Network as well as Shaping Our Lives, organisations which engaged with a broad range of disabled people and service users, including people with learning difficulties and long-term conditions. There was an emphasis on organising and offering mutual support to mental health service users/survivors who faced particular barriers – for example, if they had difficulty being in public spaces or whose distress might be particularly difficult for them to deal with at particular times – as well as on working together for change.[20]

Much was achieved in many different areas, not least a major challenge to conventional assumptions that service users could not contribute and be effectively involved.[21] Some local groups made arrangements with local hospitals and service providers, enabling members to be on wards to offer information, advice and advocacy. Schemes for collective as well as self-advocacy developed. Service users began to establish user-run services, providing crisis, out-of-hours, advocacy, advice, support and telephone services based on shared experience and first-hand knowledge. Some service users gained skills as survivor/user trainers and took part in academic and in-service training for professional and other mental health workers, offering insights from their lived experience. In social work, this was extended with the new social work degree introduced in 2001, leading to service users and carers being required to be part of all aspects and stages of qualifying training, with a budget from central government to facilitate this.[22]

Survivors and their organisations became involved in processes of service monitoring, quality control, audit, evaluation and review. Perhaps most significantly, the mental health service user movement has developed its own survivor research and research initiatives. Not

only have these offered fresh insights on mental health policy and practice, as well as distress from the perspectives and lived experience of survivors, and producing a growing cannon of both qualitative and quantitative research, but they have also resulted in the establishment of a major Service User Research Enterprise (SURE) unit at the internationally feted Institute of Psychiatry, Psychology and Neuroscience in London and also led to a growing number of survivors gaining doctorates and other research qualifications, sourcing research funding, publishing in peer-reviewed journals and securing mainstream research posts.[23] There were some early examples of user-researchers controlling their own research projects, most notably the work in the Sainsbury Centre for Mental Health and the Strategies for Living project in the 1990s;[24] but most of the efforts of user researchers have been occurring within academic spaces that have constrained the parameters of what was possible working within mainstream and services-led research projects. Nevertheless, there has been a flourishing of writing by user-researchers since the initial publication by Beresford and Wallcraft.[25]

However, while survivors and their organisations made significant progress from the 1980s onwards, it often felt from within like two steps forward and one step back. They were unable to achieve any level of funding parity in relation to traditional charitable organisations, and their significant reliance on funding from within the psychiatric system limited their independence.[26] Despite their innovative thinking about new kinds of support, few user-led services were supported or sustained in practice. Increasingly their ideas, from peer support and self-advocacy to recovery and self-management, were taken over and subverted by traditional power holders and service providers. The psychiatric system showed an enormous capacity to resist change while incorporating it at a rhetorical level.[27]

Two convincing arguments have been offered to explain mental health service users' frequent reluctance to distance themselves from conventional psychiatry even though their movement offers a clear philosophical challenge to its medical model, confirmed by research.[28] First seems to have been the fear that, if they challenge the underpinning medical model, then they will be dismissed as in denial about their own pathology and lack of rationality.[29] Second, there seems to be a more generalised reluctance to sign up to any monolithic theories about themselves for fear that these again might dominate and damage them in the same way that they feel psychiatric thinking long has done.[30] However, this has changed with the emergence of Mad studies.[31] While its flowering in the UK and internationally takes us beyond the period covered by this book, its origins and emergence can be traced to that time and therefore it has clear relevance to this discussion.

Subjectivity and Research

The narrative recounting of the user/survivor movement in the UK would be incomplete without considering the direction towards academic participation which flourished over two decades and initiated a new positioning of user-researchers into academic spaces. This generation of user-researchers took us into the struggles for legitimacy as knowers of our own experiences, holders of our own subjectivity.

Often derided by clinician researchers as of lesser credibility than its binary opposite objectivity, subjectivity designates the experience under investigation as a valid source of knowledge. Within the social sciences, decades of healthy debate and controversy surround the standing of knowledge embodied by marginalised peoples excluded from the academy and elite spaces where knowledge about their communities has been generated without their

participation. The epistemological bias has been called out by scholars from the marginalised communities, leading to critical new scholarship in, for example, feminist and women's studies, working-class scholarship and Marxist studies, critical race studies and decolonial and disability studies, all of which informed the early mental health user-researchers, and latterly the emergence of Mad studies. Disability studies, for example, fostered a reaction to able-bodied researchers describing the position of disabled people, without any benefits returning to the people studied in terms of material changes to their living situation in congregated institutionalised settings. The work of Oliver, who pioneered the idea of emancipatory disability research, inspired the early user-researchers who railed against their exclusion from knowledge generation about them by detached and objective researchers.[32]

A core element of these critical intellectual and activist endeavours is that they give value and priority to the situated knowledge of those who live with their mental health 'conditions' and under oppressive societal structures, for example physically disabled or racialised people. In the mental health field, user/survivor researchers have equally put forward the arguments that those closest to the experiences under investigation have greater tacit knowledge and insights into the phenomena being studied. This privileging of subjectivity has led to greater insights into, for instance, the experiences of hearing voices, those who self-harm, survivors of suicide attempts and those who undergo ECT.[33]

Later scholarship has illuminated the accumulated experiences of structural oppressions which have greater impact on people with other marginalised identities: racialised people, queer people and other minorities in society. The concept of intersectionality – developed by Kimberle Crenshaw– describes how black women's experiences cannot be understood by solely examining patriarchal oppressions as their racialised experiences were often ignored or silenced by white feminists and their experiences as women not understood within anti-racist movements.[34] Likewise, Kalathil has pointed out how racialised mental health service users experience intersectional oppressions due to the white majorities in the user movement spaces and sanism (prejudice and discrimination against mental health) within anti-racist movements.[35]

There is now increasing recognition of the significance of subjective experience and this has led to demands that survivors be heard and listened to as individuals and not just treated as a statistic or diagnosis. Survivors' claims for validating our subjective knowledge are core to the demands to have our stories listened to. Recent scholarship has dealt with these struggles for justice as knowers of our own experience deploying theoretical concepts such as epistemological justice.[36] Additionally, narrative therapy has led to innovations in how to recognise and address the many oppressions which induce trauma.[37] The significance of the growing evidence on the prevalence of earlier adverse experiences in people who later present to mental health services validates the movement's historical demands for listening to those who use services.[38] This has resulted in a growing demand for trauma-informed mental health services which give people space to tell their stories before arriving at any treatment decisions.

A narrative justice framework has emerged from narrative therapy and trauma work, which highlights the 'storytelling rights' of survivors of injustice and oppression. Narrative justice approaches defend people's rights to 'name their own experiences; to define their own problems, and to honour how their skills, abilities, relationships, history and culture can contribute to reclaiming their lives from the effects of trauma'; and the framework centres on an ethical question: 'When meeting with people whose problems are the result of

human rights abuses and injustices, how can we ensure we do not separate healing from justice?' The Dulwich Centre, an Australian-based narrative therapy organisation, has created a Charter of Story-Telling Rights,[39] which include the right of survivors 'to define their experiences and problems in their own words and terms' and 'to be free from having problems caused by trauma and injustice located inside them, internally, as if there is some deficit in them. The person is not the problem, the problem is the problem.' These narrative justice aims are consistent with many of the rights claimed by service users over the decades.

Citizenship

We are not isolated individuals but live in families and in societies. How people treat us once it becomes known that we have experienced distress or acquired a psychiatric diagnosis leads to the final part of our considerations, that is, struggles for citizenship. Citizenship is a concept embedded within political theory and participatory democracy, which asserts the rights of everyone to participate in a society even though not all have equal access to citizenship privileges.[40] Citizenship is linked to the notion of belonging to a society, of having rights and associated duties. In human rights legal scholarship and disability rights, disabled people are rights holders, for which the state is the duty bearer; that is, the state has obligations towards its citizens. Of course, many reject the notion of citizenship as an inclusive concept because many people around the world are denied citizenship and it is applied unequally based on difference.[41] Nevertheless, when understood in the context of second-class citizenship, it can be a useful way to examine the experiences of people with mental health diagnoses.

There is pervasive stigma and discrimination against people using mental health services (for a fuller discussion, see also Chapter 27). However, we draw attention to a specific aspect of discrimination against psychiatrised people and the way it denies them full citizenship and most essentially epistemic justice as knowers of our own realities. Sanism, a term coined by Perlin, is expanded on in greater depth by Mad scholars.[42] Sanism, they argue, operates to deny us credibility and citizenship, positioning us as lesser citizens. Indeed, sanism is used to justify separate laws to treat people against their will, as mental health legislation is drawn up by governments to address this anomaly in citizenship and human rights.[43]

The legal basis for state violence, as identified by early advocates against forced removal to psychiatric establishments and treatment imposed by medical experts against one's will,[44] has been described as akin to kidnapping. Lindow has argued that any other people undergoing forced removal and interventions experienced as traumatic would receive post-traumatic counselling and support.[45] It is this practice along with the institutionalisation of many people, preventing full participation in society, which were the primary concerns of the many psychiatric survivors who participated in the negotiation of the UN Convention on the Rights of Persons with Disabilities (CRPD) (see Chapter 8). Detailed discussion of the UN CRPD is beyond the scope of this chapter, but there is a wide and growing body of literature and activism considering the rights of people to live lives where they are fully encouraged to be active in their communities and it warrants serious attention from all areas of psychiatry and all mental health professionals.[46]

Conclusion

Our account concludes at the point where new knowledges have blossomed due to international collaborations enabled by developments in internet access and the arrival of survivor researchers and Mad scholars into academic spaces. It is necessarily short and

incomplete, as a full narrative would itself fill volumes. It is offered in an attempt to introduce readers to work that is usually ignored, undervalued and struggling for adequate funding which would allow the work to blossom further and demonstrate its potential to contribute to practice both inside and independently of mental health services.

Key Summary Points

- The user/survivor movement represents a most significant development in mental health and therefore demands careful and serious examination, particularly in its broader social, political, policy, cultural and economic contexts.

- Generations of psychiatrists have not been educated about the activism and achievements within the user/survivor movements, which left many practitioners ignorant of the autonomy and agency achieved over the past fifty years.

- The UK mental health service users/survivor movement is one of the 'new social movements' (NSMs), including black civil rights, women's, LGBTQ and grey power, emerging globally in the second half of the twentieth century, largely based on shared identity and common experiences of oppression.

- The survivor movement, like other service user movements, was facilitated by the political shift to the right from the late 1970s which was associated with a renewed emphasis on the market, devaluing of the state and growing government rhetoric for consumer rights in public services. While this did not necessarily chime with service users' calls for more say and empowerment, it opened doors to them and heralded a new stage in the broader interest in democratisation and public/user participation.

- In the mental health field, user/survivor researchers have put forward the arguments that those closest to the experiences under investigation have greater tacit knowledge and insights into the phenomena being studied.

Notes

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