SOURCES IN THE HISTORY OF PSYCHIATRY, FROM 1800 TO THE PRESENT

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The history of psychiatry is a history of power and discipline, but it is also one of solidarity and resistance. This chapter will explore some of the ways in which people deemed 'mad' or 'mentally ill' have organised themselves in opposition to the medical and legal structures which have governed their lives. Rather than concentrating on mainstream pressure groups and charities, whose histories are often well established, my focus here is on self-organised, grassroots initiatives among psychiatric patients, about which much less has been written and for which documentary evidence is scarcer.

The organised movement for liberation and recognition among those who have been on the receiving end of psychiatric treatment has gone by a variety of names, and the people involved have identified in different ways at different times and in different contexts. As such, this chapter will refer at various points to mental patients, Mad activists, ex-patients, service users, and consumers, as well as to the terms with which probably the larger number of activists in the UK now identify – survivors, and the survivor movement. In doing so, I do not intend to express a political preference for one term over another – all of which have been contested – but where possible to use the terminology appropriate to the material being discussed. Likewise, in making reference at times to 'mental patients', 'mad' people, or 'lunatics' – terms which have often been used pejoratively, or which today may be considered offensive – I have tried to match my own words to those used by historical actors of the relevant period.

The chapter will start by giving a brief outline of the history of mental health activism, chiefly focusing on developments in Britain, before going on to discuss the practical difficulties of finding and accessing source documents relating to the survivor movement, and the different kinds of materials that make up the activist archive. I will explore the ways in which these sources can tell us not just about the history of activist movements, but of psychiatry more broadly, opening up

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critical new perspectives on medical histories 'from below'. Finally, I will reflect on some of the theoretical contributions made by service user activists and historians and suggest how engaging with activist sources might change the ways in which we write histories of psychiatry.

A brief history of the survivor movement

For as long as psychiatry and asylums have existed they have been objects of controversy and criticism, subject to near-constant calls for reorganisation and reform. Going back several centuries, we can also find instances of individuals who have been diagnosed or institutionalised as insane speaking out against the ways they have been treated. The emergence of organised activism among those on the receiving end of psychiatry, however, is a decidedly modern phenomenon. There is little evidence of collective and sustained action among patients before the nineteenth century, or of anything that could be called a survivor movement before the twentieth.

The first well-documented instance of collective campaigning among people who had been designated mad is also a somewhat anomalous one, being separated from later survivor organisations both in time and by its social composition. Formed in 1845, the Alleged Lunatics' Friend Society brought together former asylum inmates who argued that they had been wrongfully incarcerated. ¹ In contrast to most later survivor groups, its members were drawn from the elite of British society, with one of its founders, John Perceval, the son of assassinated Prime Minister Spencer Perceval. Often drawing on members' personal connections, the Society lobbied for changes in lunacy laws, particularly regarding procedures for certification, and sought to draw public attention to the 'cruel and improper' treatment of patients in asylums. In some ways anticipating the kinds of advocacy work that would be taken up by later organisations, the group would also take up individual cases of incarcerated lunatics, providing legal advice, and in some cases managing to secure their release. Though the group remained active into the 1860s, there seems to have been little continuity between this early example of patient-led campaigning and the activist groups that would emerge in the following century. In the intervening decades, organised demands for reform within mental health instead came from non-patient led groups, politicians, and charity organisations.

For the purposes of this chapter, we will be looking at the sources of survivor activism as it emerged (or re-emerged) in the later part of the twentieth century. In a number of western countries, the late 1960s and early 1970s saw the nearsimultaneous formation of self-organised campaigns among psychiatric patients and ex-patients. This was a period characterised by a wave of 'new social movements' globally - including the black civil rights movement, anti-war campaigns, student protests, and women's and gay liberation. The counterculture of the 1960s had also seen the popularisation of radical 'anti-psychiatrists', such as

R.D. Laing and David Cooper in the UK, who challenged dominant medical models of psychiatry from within the profession.

While the relationship between anti-psychiatry and patient-led liberation movements has been the subject of considerable controversy among historians and activists, some of the groups that formed at this time did coalesce around dissident professionals, even if some would later distance themselves. In Italy, for example, the Psichiatria Democratica movement, led by the reforming psychiatrist Franco Basaglia, campaigned throughout the 1960s and 1970s against the asylum system, establishing co-operatives of workers and patients in several cities as an alternative to traditional institutions, and eventually winning a change in the law to bring about the closure of asylums.³ In West Germany, patients at the psychiatric hospital of the University of Heidelberg organised around the Marxist psychiatrist Wolfgang Huber, forming a general assembly of patients to establish the Socialist Patients Collective (or SPK). Around the same time in France, the Asylums Information Group, initially created by a politicised grouping of junior psychiatrists, was itself rapidly taken over by psychiatric patients, who formed alliances with the professionals to campaign against their treatment.⁵ Elsewhere, however, patient groups emerged independently. In North America, the early 1970s saw a wave of autonomous activism, with the Insane Liberation Front (Portland, Oregon), the Mental Patients' Liberation Project (New York), the Mental Patients' Liberation Front (Boston), the Mental Patients' Association (Vancouver), and the Network Against Psychiatric Assault (San Francisco), all formed in the vears between 1970 and 1972.6

The most significant group to form in Britain in this period was the Mental Patients Union (MPU), established at the Paddington Day Hospital in London in March 1973. While some professionals (psychiatric social workers rather than psychiatrists) were involved in starting the Union, full membership of the organisation was limited to patients and ex-patients. The MPU's founding *Declaration of Intent* condemned 'the institution of repressive and manipulative psychiatry', and announced its intention to 'represent mental patients wherever they require to be represented'. By 1974, the organisation had evolved into a national Federation of Mental Patients' Unions, with groups in a number of British towns and cities, including branches in psychiatric institutions.

This initial wave of patient activism was characterised by an ethos of self-organisation and an uncompromising rejection of medical authority. The MPU had been preceded, in 1971, by the shorter-lived Scottish Union of Mental Patients, and also by the looser network of People Not Psychiatry, started in 1969, which aimed to provide non-medical alternatives to psychiatric institutionalisation. Many of the members of these groups had links to left-wing politics and embraced the counterculture of the period. Later in the 1970s, some MPU members moved into new groups such as PROMPT (Protection of the Rights of Mental Patients in Therapy), which in 1985 became CAPO (Campaign Against Psychiatric Oppression), adopting the aesthetics of the contemporary punk scene and direct-action tactics influenced by radical political groups.

At the same time, however, from the mid 1980s, a new wave of user-led organisations was emerging which attempted to build a broader base of support engaging with professionals, mainstream mental health charities, and non-survivor 'allies'. New initiatives within mental health services to solicit patient involvement in provision, for example through the 1990 NHS and Community Care Act, paved the way for a shift in terminology from 'patients' to 'consumers' and 'service users', facilitating a proliferation of patient representation and advocacy groups. This was also the period in which the term 'survivors' came into widespread currency, with Survivors Speak Out (SSO) formed in 1986 as a national network to facilitate and coordinate action among the growing number of local groups. The United Kingdom Advocacy Network (UKAN), formed in 1990, performed a similar national coordinating function, promoting individual and collective selfadvocacy for users of mental health services. There were also new groups coalescing around particular diagnoses or issues in mental health, for example around voice-hearing, self-harm, and eating disorders, as well as groups of survivors linked by identity categories relating to race and ethnicity, gender and sexuality. 10

From the late 1990s, activists under the banner of Mad Pride have increasingly embraced madness as an identity category in itself, with its own distinctive culture and community, and which is deserving of political recognition. Taking inspiration from Gay Pride and the struggles of other marginalised groups, these activists have sought to reclaim the term 'mad', rejecting the medicalisation of so-called psychological disorders and seeking to reverse the negative connotations associated with madness.

Finally, since the financial crash of 2008, and the imposition of austerity policies in the UK by Conservative-led governments, a new wave of politicised mental health activism has developed. This has been defined by opposition to cuts to services, and an emphasis on the psychological costs of socioeconomic deprivation and inequality under neoliberal capitalism. The increasing imbrication of mental health services with the welfare system has also seen growing overlap between survivor groups and disabled people's activism, in organisations such as Disabled People Against the Cuts, the Mental Health Resistance Network, and Recovery in the Bin.

Finding the activist archive

One of the major challenges facing the historian of survivor movements is finding relevant material. Much of what is produced by activist organisations is ephemeral, with posters, flyers, and correspondence often not kept. Many of the activities undertaken by such groups - meetings, protests, and other events - do not necessarily leave an archival trace. Unlike the medical journals of psychiatrists, the minute books of professional bodies, or the administrative records of asylums, the documents of the survivor movement have not always been carefully or systematically preserved. The activist archive gets dispersed among the various groups and individuals who create and use it, often remaining hidden in private homes, unknown or inaccessible to researchers.¹¹ While recent years have seen some efforts to link up these scattered collections or to catalogue their contents, gaining access to many of these materials can often be a hit-and-miss process of attempting to cultivate personal connections with groups or individuals.

Much of the historiography that exists about the survivor movement has been written by activists themselves, who have often taken a keen interest in recording and documenting their own history. As will be explored later, survivors telling their own stories or testifying to their own experiences can be an activist act in itself, a means of asserting ownership over experiences which have more often been framed in the words of others. One of the richest source bases for historians of survivor activism, then, are the accounts of the movement written by campaigners. Histories written by participants can blur the distinction between primary and secondary sources, combining research with personal memory, scholarship with autobiography, and historical description with political interpretation.

One of the first book-length accounts of the activities and philosophy of the mental health liberation movement is the American survivor activist (and later historian) Judi Chamberlin's On Our Own: Patient-Controlled Alternatives to the Mental Health System. First published in 1978, the book describes Chamberlin's involvement in the early activities of the Mental Patients' Liberation Front in Boston, and a number of other early survivor groups in the 1970s. Her account of the movement is enriched by conversations with other activists and excerpts from the campaign literature of the period, and an appendix to the book includes a 'list of alternative facilities, organisations, and publications', predominantly in the US, but also Canada, Belgium, England, France, the Netherlands, and New Zealand.

In the UK, too, the first histories of the movement were written by activists, with Peter Campbell's 1996 essay, 'The History of the User Movement in the United Kingdom', an important early example. In 2003, a larger survivor-led research project into the movement and its history was published under the title On Our Own Terms, drawing on surveys and interviews with over 300 people active in user-led groups. In 2005, building on these survivor-led approaches, a group of survivors and activists came together to form the Survivors History Group (SHG), initially conceived of as a project 'to rescue the physical history of the mental patients' movement from the skip'. Over the years, the SHG has done an enormous amount of work to record and catalogue the various private collections of archival material held by individuals involved in the movement, as well as publishing its own histories, responding to the work of other historians, and creating forums – both online and in person – to discuss 'the contribution that mental health service users/survivors have made and are making to history'. In the contribution of the survivors have made and are making to history'.

Of particular importance and value to historians is the SHG website, created and maintained by Andrew Roberts, a founding member of the MPU and one of the movement's most prominent historians and archivists.¹⁷ A sprawling enterprise, the site contains a vast wealth of material for the historian of survivor movements including: timelines of mental health history and of survivor movements; bibliographies of secondary material on user movements, and of published

and unpublished works by survivors; histories of the movement in the 1970s, 1980s, and 1990s written by activists from each period; and a catalogue (in progress) of the vast collection of archival material which Roberts currently holds at his home in London. A number of previously unpublished primary documents have also been made digitally available through the site, either scanned as images or typed, further opening up the activist archive and making it accessible to new audiences. The SHG website - through Roberts - has also acted as a hub for researchers keen to make contact with those active in the movement, or to make use of their personal archives.

Despite the lack of public collections dedicated to survivor activism in the UK, it is still possible to trace the history of the movement through traditional archives and libraries. While many of the more ephemeral publications have not been preserved, survivor activism has occasionally attracted wider attention and has left traces in less immediately obvious places. Often, this has been in archives associated with other radical or countercultural movements. Hannah Proctor, for example, has drawn on the archive of the socialist organisation Big Flame, held at the May Day Rooms in London, to uncover the story of Red Therapy, a leaderless self-help group started by left-wing activists in London in the late 1970s, while Sarah Crook has traced the development of similar groups within the Women's Liberation Movement through the feminist press. 18 For historians looking to follow stories of activism in radical publications, specialist archives like the Bishopsgate Institute and the Feminist Library in London, or the Working Class Movement Library in Salford, can provide a wealth of sources, as can the extensive collections of the British Library. The early history of the MPU, for example, can be traced sporadically through titles including Time Out, Socialist Worker, Peace News, and People's News Service, as well as in some of the smaller papers associated with radical psychology, such as Red Rat and Humpty Dumpty. More occasionally, survivor activism – and protests in particular – have caught the attention of the mainstream press, with local newspapers and local authority archives a good route for tracking the activities of smaller groups.

One of the few British publications relating to the survivor movement to be archived in its entirety is Asylum: A Magazine for Democratic Psychiatry, which has been published near-continuously since 1986. The complete back catalogue is now held at the Wellcome Library in London. While initially created by radical professionals - taking inspiration from the Italian Psichiatria Democratica movement -Asylum has from its earliest editions been an important and welcoming outlet for service users, and in recent years has given increasing precedence to survivor voices. A current project by Helen Spandler - a member of the magazine's editorial collective - has, among other things, shed light on Asylum's longstanding coverage of service user activism and its links to the movement. 19 Early issues dedicated features to Survivors Speak Out and CAPO, while more recently editorial control has been given over to activist groups, such as the Mad Hatters of Bath, who presented a Mad Pride special issue in 2011.²⁰

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Spandler's work on Asylum also reminds us that the sources of survivor activism are not just textual. As she notes in a recent chapter, survivors have made effective use of visual 'styles of contestation', in particular cartoons and comic strips, as a means of conveying political messages in concise and accessible ways, with activists often deploying humour as a 'form of covert resistance'. ²¹ In survivor activism, jokes, cartoons, illustrations, and other creative forms have featured prominently. Some of the radical groups of the 1980s had strong links to London's alternative music scene, and would often combine protest with performance, a tradition continued in later decades through Mad Pride's 'celebration of mad culture'.²² Frank Bangay, an activist with PROMPT and CAPO, has also been a key figure in the Survivors' Poetry movement, seeing poetry as a way 'to help change attitudes and break barriers down'. 23 His 1999 collection, Naked Songs and Rhythms of Hove, combines poetry and drawing with annotations on his experiences of psychiatric treatment and his involvement in activism.²⁴ When read alongside other activist sources, such documents can provide a valuable personal or emotional perspective often missing from more directly political publications.

As well as the written and visual records that we can discover in these diverse activist archives, historians of the survivor movement have also made use of oral history interviews. The comparatively recent development of survivor activism as a phenomenon means that talking to people directly involved even in the early years of the movement's history is often still possible, and the relative scarcity of easily accessible documentary sources has made this an attractive option for historians and other researchers. The particular challenges of oral history are covered in Victoria Hoyle's chapter in this volume.

As we approach the present day, the archive of survivor activism is increasingly being created online. The internet has made possible resources like the SHG website, the uploading and sharing of documents, photographs, and videos which might previously have languished in attics, and the forging of new connections between activists and historians. At the same time, for groups active today, the internet is increasingly a site of activism in its own right, and social media pages in particular are becoming an immediate repository for the archives of contemporary social movements.²⁶

In some ways, these social and technological developments promise an abundance of source material for historians of activism, with a range of new media and visual formats, such as memes, requiring researchers' scrutiny.²⁷ At the same time, however, the accelerated pace of production and consumption of activist content online, and the dependence for its preservation on private companies whose approaches to the collection and use of data are often extremely opaque, in some ways make this new kind of archive even more precarious and ephemeral than the physical documents of earlier groups. In addition, while social media promises a wealth of new source material, the repurposing by researchers of posts made online from personal accounts – particularly when they discuss an individual's medical history or their political activity – raises difficult questions around anonymity and informed consent. How researchers should manage or engage with the vast

amounts of data created daily online is a methodological and ethical problem which has only recently begun to be theorised, but it is one that historians of survivor activism will increasingly need to pay attention to.²⁸

Activist sources and the history of psychiatry

Beyond the important task of reconstructing the history of the survivor movement itself, activist sources can also be a valuable resource for historians of psychiatry more broadly. Since the 1980s, the discipline has been increasingly concerned with writing histories 'from below'. Rather than approaching the history of psychiatry from the perspective of the medical profession - looking at the evolution of diagnoses or particular treatments, for example – this kind of history instead privileges, as an influential 1985 essay by Roy Porter put it, 'the patient's view'.²⁹

Building on Porter's work, Anne Rogers and David Pilgrim suggested in a 1990 article, built around interviews with activists, that research on the mental health service user movement could provide an 'alternative perspective' to professional and academic discourses which tend towards depicting the patient 'as existing as a by-product of a particular clinical gaze'. Rather than viewing those in psychiatric care as 'passive victims of government policy', or as a mere effect of 'economic and social structures' beyond their control, this type of work could emphasise the agency of psychiatric patients, and their collective role in establishing new agendas in the field of mental health. 30 However, with a few notable exceptions (often from survivor researchers), activist material has remained a significantly underused resource among even those historians of medicine who have attempted to foreground patient voices.

Psychiatric histories from below have often relied on memoirs, autobiographies, diaries, and other forms of first person life-writing - often written by middle- or upper-class patients. Rather than a fundamental reorientation of the historical perspective, critics have argued, the result has been an accumulation of individual cases, which remain 'enclosed in their singularity', and which are heavily determined both by the social positionality of the author and by the narrative conventions of published memoirs.³¹ Moreover, in taking Porter's lead and focusing on the 'medical encounter' between patient and doctor, historians have often ended up reproducing a narrow understanding of the patient only insofar as they have been constructed through their interaction with medicine. Few have taken up Rogers and Pilgrim's call for a greater understanding of 'the wider collective role of consumers as a group within civil society', or even as a 'movement'. 32

In contrast to the individual memoir, activist sources can often provide historians with a more collective approach to survivor testimony. The 1986 film We're Not Mad, We're Angry, for example, originally broadcast on Channel 4's Eleventh Hour programme (and currently available on YouTube), was created collaboratively by patients and activists, with full editorial control of the production.³³ The hour-long film is composed mostly of direct-to-camera interviews, with survivors detailing their experiences of mental illness and the psychiatric

system, both in hospital and in the community. Participants describe being sectioned under the Mental Health Act, and living with the stigma attached to psychiatric diagnoses. They discuss their experiences of psychiatric medication, occupational therapy, and forced treatment including electroconvulsive therapy (ECT). They describe abuse and humiliation at the hands of staff, and institutional racism, sexism, and homophobia. In a series of short narrative segments, written by Peter Campbell and performed by fellow survivors, the 'patient's view' is literalised through the camera, as the viewer is placed in the shoes of 'Alice', adopting her perspective via long, continuous point-of-view shots, as we follow her through the psychiatric system.

One objection to drawing on activist sources of this kind as a source for understanding the psychiatric system might be that activists are not 'typical' service users, or representative of the wider patient experience. It might be argued that most people who are diagnosed with a mental health condition, or who use mental health services, do not become activists, and the negative portrayals of psychiatry within activist sources are therefore unlikely to be reflective of wider currents of opinion. On closer inspection, though, such arguments are difficult to sustain. Throughout the history of the survivor movement, activists have been dismissed in similar terms, and not just by historians. As the authors of *On Our Own Terms* put it:

Many of us have been accused of not being typical users. We are told we are too articulate and educated, or too angry and radical, too well, too ill, or in some way different from the majority of 'ordinary' service users. Most often that accusation comes from professionals, but sometimes it comes from other service users/survivors. It can leave us rather confused. Who are the 'ordinary' service users? Are they the ones with the most severe and acute problems, which leave them too vulnerable to cope with involvement? Or are they people who are being made better by their treatment and don't wish to complain?³⁴

As activists have often been the first to point out, there is no such thing as the 'typical' patient, or a single, uncomplicated survivor 'experience'. Neither are survivor activists themselves a homogenous 'community'. User groups have encompassed a wide range of ideological viewpoints, tactical strategies, and positions with respect to controversial issues such as diagnosis, medication, and the role of non-survivor 'allies'. As the survivor activist and academic Diana Rose has demonstrated, 'there is a difference between being "representative" and striving to "represent" a collective discourse of contention, collaboration and change'. Precisely because activists do speak out – arguably insofar as they *are* unrepresentative in this sense – their contributions are of use to historians seeking to understand how the mental health care system operates in practice, disturbing easy narratives of medical hegemony and psychiatric progress.

Because the politics of mental health liberation are so often grounded in people's experiences of psychiatric systems, activist materials can provide us with important

information about how these systems have worked in practice that is unlikely to be recorded in official sources. In forming the Scottish Union of Mental Patients, for example, patients at Hartwood Hospital produced a list of 'tabulated grievances and some suggested remedies', which they presented to visiting Mental Welfare Commissioners in 1971. The document, held in the private SHG archive but also summarised and quoted on the website, contains accounts of specific injustices committed against individual patients, as well as more general complaints about conditions, with demands ranging from the abolition of the parole system and the stratification of patients to improving the quality of food in the hospital canteen. ³⁶ A little under two years later, the MPU produced their own Declaration of Intent, following a meeting of over 100 patients from across the UK. In the document (the full text of which is also available on the SHG website), activists highlight censorship of communications by hospital authorities, confiscation of patients' clothing and personal belongings, the forcible detention of 'voluntary' patients, the exploitation of patients' labour through occupational therapy, lack of informed consent in treatment, the use of 'treatments' as punishments, and the use of solitary confinement for resistant or difficult patients.³⁷

Frequently, groups have attempted to canvass the wider population of service users to gather information on their experiences and opinions of psychiatric treatment. One of the first projects of the MPU, for example, was to design a questionnaire to be distributed to members and in hospitals, inviting respondents to detail their own medical history, their experiences of psychiatric treatment, and their concerns and complaints. The returned forms provide a snapshot of psychiatry in the early 1970s, with a diverse collection of views from patients from a range of types of institution. Together, they help us to build a picture of some of the ways in which individuals were able to negotiate institutionalisation and treatment, or to understand or influence their own situations. One woman describes a two-year involuntary stay at a Welsh psychiatric institution and her fears of readmission: 'I am afraid to be myself in case I find myself back in hospital. I am acting a part and sometimes I get desperately tired of it.' In hospital she finds herself 'having to exercise an iron self control in case display of feeling got me a "bad mark"". Another respondent from a London hospital recalls: 'The staff was all right if you dident [sic] bother them with your problems.'38

Service user groups have also produced practical materials to help people navigate the psychiatric system, often explicitly promoted as alternatives to information provided through official channels. In 1975, MPU activists in London researched and published A Directory of the Side Effects of Psychiatric Drugs, a tenpage pamphlet aimed at helping patients understand the risks associated with common medications, now held in the SHG's private collection. ³⁹ In Manchester, the local MPU branch published Your Rights in Mental Hospital, outlining the provisions of the Mental Health Act as they pertained to patients, and their operations in practice. 'The law gives power over you to your nearest relative, your social worker, your GP, your psychiatrist, the hospital, the Home Secretary and the police', wrote the authors of the latter pamphlet. 'We think that part of getting better is taking some of that power back. To do this ... you need to understand the situation you're in.'⁴⁰ In the same vein, from the 1980s onwards, with the rise of 'user participation' in mental health care, survivor groups produced or contributed to a variety of practical guides to patient representation and self-advocacy.

With the emergence of Mad Pride over the last two decades, and its celebration and promotion of Mad culture, historians can now draw upon a whole range of activist sources that take us beyond the medical encounter and the hospital, expanding beyond conventional narratives of illness, treatment, and recovery to embrace a range of genres, topics, and styles. The movement has emphasised, as the editors of an eclectic 2003 *Mad Pride* writing collection put it, 'that "madness" is as much to do with sex, drugs and rock 'n' roll [as] with the "long echoing corridors" described repeatedly by survivor poets'. ⁴¹ Perhaps the creative and experimental output of writers and artists associated with Mad Pride can help historians of psychiatry find our way out of our own narrow asylum corridors, to begin to approach survivor subjectivities and cultures in a fuller and more expansive light.

Activism and the practice of history

As we have seen, survivor activists have often been deeply invested in writing the history of their own movement. Mental health activism and historiography have often been intimately intertwined, with history-writing a key means by which survivors have been able to assert their status as political actors and agents of change, challenging the passive status too often ascribed to them by both the medical establishment and conventional histories of psychiatry. 'Like other liberation struggles of oppressed people,' Judi Chamberlin wrote in 1990, 'the activism of former psychiatric patients has been frequently ignored or discredited. Only when a group begins to emerge from subjugation can it begin to reclaim its own history.'42 More recently Jayasree Kalathil has emphasised the importance of documenting developments within the survivor movement (in this context as they relate to the involvement of Black and ethnic minority service users) as a means to 'learn from our experiences, celebrate our achievements and create our own history'. 43 Establishing the long-term continuity of survivor activism has helped to provide a 'usable past' for campaigners, who have been able to draw on the history of the movement for encouragement, inspiration, and models of action.⁴⁴

Beyond the movement's own history, survivor activism has also contested mainstream histories of psychiatry more broadly, and in doing so, poses important challenges to the practice of historians in the field. These critiques have centred broadly on three interrelated questions: the place of survivor stories within the history of psychiatry, the subject-position of the person telling these stories, and what counts as legitimate historical evidence or source material.

These debates were spectacularly dramatised in 1997, when the Bethlem and Maudsley NHS Trust announced plans to 'celebrate' the 750th anniversary of the notorious Bethlem Royal Hospital with a series of public events, and an exhibition at the Museum of London. Despite plans for a single 'user's day' to be included

within the programme of events, there had been no consultation with current or ex-patients and, crucially, the stories of survivors were excluded from the version of history espoused by the Trust. Many of those involved in user activism saw nothing to celebrate in 'a history that from its earliest days reveals a familiar catalogue of inquiries, scandals, abuse and inhumanity', and challenged the exhibition's presentation of medical history 'in classic modernist terms of centuries of progress, culminating in modern psychiatry and the Maudsley Hospital'. 45

In response, the Reclaim Bedlam campaign, started by Pete Shaughnessy – a former Maudsley patient active in local user groups - sought to challenge both the exclusion of survivors inherent in the anniversary events and to present an alternative narrative to that promoted by the hospital: a 'commemoration' of the lives of those who had suffered, and continued to suffer, under psychiatry's regime, as opposed to a 'celebration' of medical progress. ⁴⁶ Protestors held a carnival 'picnic' – 'Raving in the Park' – at the former Bethlem site at the Imperial War Museum, and picketed an anniversary 'thanksgiving' service at St Paul's Cathedral, holding a minute's silence 'for people who have died of distress or at the hands of the mental health system over 750 years'. 47

Reclaiming psychiatry's history for survivors has meant contesting the narratives that are presented and used by historians, the medical profession, and other non-survivor organisations. Events and projects organised by activist groups – such as the Health Through History writing collective run by Tower Hamlets African and Caribbean Mental Health Organisation, the Oor Mad History initiative among survivor groups in Lothian, Scotland, or the Pageant of Survivor History organised by F.E.E.L. (Friends of East London Loonies) in 2011 - have decentred professional knowledge and celebrated survivor histories. At the same time, campaigns like Reclaim Bedlam have also been about challenging who can legitimately tell such histories in the present, about what kinds of evidence or knowledge should be privileged in the telling, and the political implications that different kinds of histories entail. Writing a year after the Bedlam anniversary, the activist and academic Peter Beresford argued that 'if mental health service users/ survivors are to take charge of our future', then it was essential also to take back control of a past, which, 'at both individual and collective levels, has been largely appropriated, denied, controlled and reinterpreted by other powerful interests'. 48

Adopting the imperative of 'nothing about us without us' developed within the wider disability rights movement, activists in recent years have asserted the need for research in mental health to include not only the perspectives but the active participation of those on the receiving end of psychiatric treatment, 'balancing the overwhelming majority of material written about those who are labelled mad by those who do the labelling and those who study them'. 49 Participatory forms of research have championed the value of previously marginalised 'experiential' knowledge, challenging positivist and professional-centred approaches to mental health and advocating constructive dialogue between researcher and researched.⁵⁰

While these conversations have so far largely taken place in relation to health research and the design of services, recent activist interventions, particularly in the

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burgeoning field of Mad Studies, remind us that not only medical professionals, but also historians can be counted among 'those who study those who are labelled mad', and have often been complicit – even as 'allies' – in the exclusions, cooptions, and unequal power relationships that survivors have sought to challenge. As the Survivors History Group have argued, whereas 'the academic historian/sociologist may only be concerned to find some rough fit between theoretical models and data ... the detail of history matters to us because it bears on our lives and our heritage'. Foundational to the SHG project is the principle that 'service users own their history'. Foundational to the SHG project is the principle that

For historians of psychiatry – particularly those who are not mental health service users or survivors themselves – the challenges posed by these interventions are substantial, but taking them seriously can enrich our practice. We might think, for example, about how models of 'co-production' pioneered in survivor research might be applied to the work of history, bearing in mind the historian Katie Barclay's observation that 'all encounters with others, but not least through writing, involve at least two people'. ⁵⁴ This would mean handling survivor source material – whether an interview with a living person sitting in front of you, or an anonymous scrap of writing in an archive – with an attitude of openness and collaboration; seeing service users not simply 'as a source of experiential data', as Peter Beresford and Jan Wallcraft put it, but 'as creators of our own analysis and theory'. ⁵⁵

In this chapter I have tried to emphasise the value of activist sources not just as a narrow window onto the history of the survivor movement, critical though such histories are, but as a diverse body of work which can provide new perspectives on the history of psychiatry more broadly. In setting out the range of activist materials available for research, I have hopefully suggested some promising leads for other historians to pursue. The sources referred to here give only a glimpse of the range of groups, activities, and political orientations which have characterised the survivor movement in recent history, and – largely due to my own research limitations – have been drawn almost exclusively from the British movement. As new research into the global dimensions of the survivor movement is demonstrating, there are many more unexplored source bases for historians to investigate, and with the activist archive being added to daily online and on the streets, there will be plenty of opportunities for new histories to be written.⁵⁶

Notes

- 1 Nicholas Hervey, 'Advocacy or Folly: The Alleged Lunatics' Friend Society, 1845–63', *Medical History*, 30, 3 (1986), pp. 245–75.
- 2 Alleged Lunatics' Friend Society pamphlet (1846), quoted in Sarah Wise, *Inconvenient People: Lunacy, Liberty, and the Mad-Doctors in England* (Berkeley, CA: Counterpoint, 2013), p. 79.
- 3 John Foot, The Man Who Closed the Asylums: Franco Basaglia and the Revolution in Mental Health Care (London: Verso, 2015).
- 4 Helen Spandler, 'To Make an Army out of Illness: A History of the Socialist Patients' Collective Heidelberg 1970–2', *Asylum*, 6, 4 (1992), pp. 5–12.

- 5 Jacques Lagrange, 'Course Context', in Michel Foucault, Psychiatric Power: Lectures at the Collège de France, 1973–1974, ed. Jacques Lagrange, trans. Graham Burchell (New York: Picador, 2008), p. 353.
- 6 Judi Chamberlin, 'The Ex-Patients' Movement: Where We've Been and Where We're Going', Journal of Mind and Behaviour, 11, 3 (1990), pp. 326-7.
- 7 Helen Spandler, Asylum to Action: Paddington Day Hospital, Therapeutic Communities and Beyond (London: Jessica Kingsley Publishers, 2006), pp. 52-67.
- 8 Survivors History Group Archive (SHG), Mental Patients' Union, Declaration of Intent (1973).
- 9 Mark Gallagher, 'From Asylum to Action in Scotland: The Emergence of the Scottish Union of Mental Patients, 1971-2', History of Psychiatry, 28, 1 (2017), pp. 101-14; Michael Barnett, People Not Psychiatry (London: Allen & Unwin, 1973).
- 10 For examples see Adam James, Raising Our Voices: An Account of the Hearing Voices Movement (Gloucester: Handsell Publishing, 2001); Mark Cresswell and Tom Brock, 'Social Movements, Historical Absence and the Problematization of Self-Harm in the UK, 1980–2000', Journal of Critical Realism, 16, 1 (2017), pp. 7–25; Jayasree Kalathil, Dancing to Our Own Tunes: Reassessing Black and Minority Ethnic Mental Health Service User Involvement (National Survivor User Network in collaboration with Catch-a-Fiya, 2008).
- 11 Sarah Chaney, 'Where Is the Survivor Archive?,' Wellcome Library (blog), 15 Dec. 2016, http://blog.wellcomelibrary.org/2016/12/where-is-the-survivor-archive, last accessed 5 Dec. 2020.
- 12 Judi Chamberlin, On Our Own: Patient-Controlled Alternatives to the Mental Health System (New York: McGraw-Hill, 1979).
- 13 Peter Campbell, 'The History of the User Movement in the United Kingdom', in Tom Heller, Jill Reynolds, Roger Gomm, Rosemary Mustin, and Stephen Pattison (eds), Mental Health Matters: A Reader (Basingstoke: Macmillan, 1996), pp. 218–25.
- 14 Jan Wallcraft, Jim Read, and Angela Sweeney, On Our Own Terms: Users and Survivors of Mental Health Services Working Together for Support and Change (London: The Sainsbury Centre for Mental Health, 2003).
- 15 Andrew Roberts, 'History as Research Method: The Survivors History Group,' Andrew Roberts' Home Page, 2010, http://studymore.org.uk/hisnot.htm, last accessed 5 Dec. 2020.
- 16 Survivors History Group, 'Survivors History Mental Health and Survivors' Movements and Context,' Andrew Roberts' Home Page, 2005, http://studymore.org.uk/ MPU.HTM, accessed 5 Dec. 2020.
- 18 Hannah Proctor, 'Lost Minds: Sedgwick, Laing and the Politics of Mental Illness', Radical Philosophy, 197 (2016), pp. 45-6; Sarah Crook, 'The Women's Liberation Movement, Activism and Therapy at the Grassroots, 1968-1985', Women's History Review, 27, 7 (2018), pp. 1152-68.
- 19 Helen Spandler, 'Asylum: A Magazine for Democratic Psychiatry in England', in Tom Burns and John Foot (eds), Basaglia's International Legacy: From Asylum to Community (Oxford: Oxford University Press, 2020), pp. 205-26.
- 20 'Survivors Speak Out Conference in September '87,' Asylum, 2, 1 (1987), p. 5; 'The CAPO Interview', Asylum, 3, 3 (1989), pp. 5-8; Asylum, 18, 1 (The Mad Hatters of Bath Take Over the Asylum) (2011).
- 21 Helen Spandler, 'Crafting Psychiatric Contention through Single-Panel Cartoons,' in Susan Merrill Squier and Irmela Marei Krüger-Fürhoff (eds), PathoGraphics: Narrative, Aesthetics, Contention, Community (University Park: Penn State University Press, 2020),
- 22 Robert Dellar, Ted Curtis, and Esther Leslie (eds), Mad Pride: A Celebration of Mad Culture (London: Chipmunka, 2003). See also Robert Dellar, Splitting in Two: Mad Pride and Punk Rock Oblivion (London: Unkant Publishers, 2014).

- 23 Frank Bangay, 'An Uphill Struggle, but It's Been Worth It,' in Dellar et al., *Mad Pride*, pp. 101–4: p. 101.
- 24 Frank Bangay, Naked Songs and Rhythms of Hope: An Illustrated Collection of Poems from 1974 to 1999 (London: Spare Change Books, 1999).
- 25 See for example, Anne Rogers and David Pilgrim, "Pulling down Churches": Accounting for the British Mental Health Users' Movement', Sociology of Health & Illness, 13, 2 (1991), pp. 129–48; Spandler, Asylum to Action; Nick Crossley, Contesting Psychiatry: Social Movements in Mental Health (Abingdon: Routledge, 2006).
- 26 Cayce Myers and James F. Hamilton, 'Social Media as Primary Source: The Narrativization of Twenty-First-Century Social Movements', *Media History*, 20, 4 (2014), pp. 431–44.
- 27 Lucy Johnson, '#Relatable: An Ethnography of Mental Health Memes on Instagram', MSc dissertation, University of Glasgow, 2018.
- 28 For discussions of some of these problems see Jack Dougherty and Kristen Nawrotzki (eds), *Writing History in the Digital Age* (Ann Arbor, MI: University of Michigan Press, 2013); Kandy Woodfield (ed.), *The Ethics of Online Research* (Bingley: Emerald Publishing, 2018).
- 29 Roy Porter, 'The Patient's View: Doing Medical History from Below', *Theory and Society*, 14, 2 (1985), pp. 175–98.
- 30 Rogers and Pilgrim, "Pulling down Churches", pp. 129-30.
- 31 Alexandra Bacopoulos-Viau and Aude Fauvel, 'The Patient's Turn Roy Porter and Psychiatry's Tales, Thirty Years On', *Medical History*, 60, 1 (2016), pp. 1–18: p. 12. See Flurin Condrau, 'The Patient's View Meets the Clinical Gaze', *Social History of Medicine* 20, 3 (2007), pp. 525–40.
- 32 Rogers and Pilgrim, "Pulling down Churches", p. 130.
- 33 We're Not Mad, We're Angry (Albany Videos, 1986), https://www.youtube.com/watch?v=qD36m1mveoY, accessed 22 Oct. 2020.
- 34 Wallcraft, Read, and Sweeney, On Our Own Terms, p. 32.
- 35 Diana Rose, 'A Hidden Activism and Its Changing Contemporary Forms: Mental Health Service Users/Survivors Mobilising', *Journal of Social and Political Psychology* 6, 2 (2018), pp. 728–44: p. 736.
- 36 Survivors History Group Archive, Scottish Union of Mental Patients, 'Tabulated Grievances and Some Suggested Remedies These are for the Attention of the Mental Welfare Commissioners' (1971). See http://studymore.org.uk/MPU.HTM#SUMPbox, accessed 15 Mar. 2021.
- 37 Mental Patients' Union, *Declaration of Intent*. See http://studymore.org.uk/MPU.HTM# MPUDeclaration, accessed 15 Mar. 2021.
- 38 Survivors History Group Archive, MPU Questionnaire Answers (1973).
- 39 Survivors History Group Archive, Chris Hill, Joan Martin, and Andrew Roberts, *A Directory of the Side Effects of Psychiatric Drugs* (Oct. 1975).
- 40 Private collection (Terry Simpson, Leeds), Manchester Mental Patients' Union, *Your Rights in Mental Hospital* (c.1977), p. 1. A copy of this is also held at the British Library.
- 41 Robert Dellar, Ted Curtis, and Esther Leslie, 'Introduction', in Dellar et al., *Mad Pride*, pp. 7–8: p. 8.
- 42 Chamberlin, 'The Ex-Patients' Movement', p. 323.
- 43 Kalathil, Dancing to Our Own Tunes, p. 5.
- 44 Nick Crossley, 'Working Utopias and Social Movements: An Investigation Using Case Study Materials from Radical Mental Health Movements in Britain', *Sociology*, 33, 4 (1999), pp. 809–30.
- 45 Peter Beresford, 'Past Tense. On the Need for a Survivor-Controlled Museum of Madness', *OpenMind* (May/Jun. 1998), http://studymore.org.uk/mpuhist.htm, accessed 15 Mar 2021
- 46 Pete Shaughnessy, 'Into the Deep End', in Dellar et al., Mad Pride, pp. 20-22.

- 47 Crossley, Contesting Psychiatry, p. 205. Even for such relatively recent events as these, few documents have been kept, with those that survive mostly in private collections. Researchers such as Crossley have relied on interviews with participants, as well as the brief reports that appeared in some contemporary newspapers.
- 48 Beresford, 'Past Tense'.
- 49 David Crepaz-Keay and Jayasree Kalathil, 'Introduction', in Jayasree Kalathil (ed.), Personal Narratives of Madness (Oxford: Oxford University Press, 2013), https://global. oup.com/booksites/content/9780199579563/narratives/, accessed 15 Mar. 2021.
- 50 Alison Faulkner, 'Survivor Research and Mad Studies: The Role and Value of Experiential Knowledge in Mental Health Research', Disability & Society, 32, 4 (2017), pp. 500-20.
- 51 Jasna Russo and Peter Beresford, 'Between Exclusion and Colonisation: Seeking a Place for Mad People's Knowledge in Academia', Disability & Society, 30, 1 (2015), pp. 153-7.
- 52 Survivors History Group, 'Survivors History Group Takes a Critical Look at Historians', in Marian Barnes and Phil Cotterell (eds), Critical Perspectives on User Involvement (Bristol: Policy, 2012), pp. 7–18: p. 17.
- 53 Roberts, 'History as Research Method'.
- 54 Katie Barclay, 'Falling in Love with the Dead', Rethinking History, 22, 4 (2018), pp. 459-73: p. 465.
- 55 Peter Beresford and Jan Wallcraft, 'Psychiatric System Survivors and Emancipatory Research: Issues, Overlaps and Differences', in Colin Barnes and Geof Mercer (eds), Doing Disability Research (Leeds: The Disability Press, 1997), pp. 66-87: p. 73.
- 56 See, for example, the Wellcome Trust and King's College London's EURIKHA initiative, 'a global research project looking at the emergence of social movements which privilege the rights and perspectives of people who experience severe mental distress.' 'Who Are We, and Why Are We Here?,' EURIKHA, 19 Feb. 2018, https://www. eurikha.org/blog/who-are-we-and-why-are-we-here/, accessed 15 Mar. 2021.

Select bibliography

- Barnes, M. and Cotterell, P. (eds), Critical Perspectives on User Involvement, Bristol: Policy, 2012. Chamberlin, J., 'The Ex-Patients' Movement: Where We've Been and Where We're Going', Journal of Mind and Behaviour 11, 1990, pp. 326-327.
- Crossley, N., Contesting Psychiatry: Social Movements in Mental Health, Abingdon: Routledge, 2006. Dellar, R., Curtis, T., & Leslie, E. (eds), Mad Pride: A Celebration of Mad Culture, London: Chipmunka, 2003.
- Gallagher, M., 'From Asylum to Action in Scotland: The Emergence of the Scottish Union of Mental Patients, 1971-2', History of Psychiatry 28, 2017, pp. 101-114.
- Hervey, N., 'Advocacy or Folly: The Alleged Lunatics' Friend Society, 1845-63', Medical History 30, 1986, pp. 245–275.
- Kalathil, J. (ed.), Personal Narratives of Madness, Oxford: Oxford University Press, 2013.
- Rose, D., 'A Hidden Activism and Its Changing Contemporary Forms: Mental Health Service Users/Survivors Mobilising', Journal of Social and Political Psychology 6, 2018, pp. 728-744.
- Russo, J. & Beresford, P., 'Between Exclusion and Colonisation: Seeking a Place for Mad People's Knowledge in Academia', Disability & Society 30, 2015, pp. 153-7.
- Spandler, H., 'Asylum: A Magazine for Democratic Psychiatry in England', in T. Burns and J. Foot (eds), Basaglia's International Legacy: From Asylum to Community, Oxford: Oxford University Press, 2020, pp. 205-226.