

## Final Accepted Version

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This chapter uses the Wellcome Library's archive collecting around the treatment and experience of the mad as a case study for exploring the opportunities and challenges that arise from mainstream attempts to introduce counter-narratives into the archive. The observations drawn out from this chapter are based on observations at the Wellcome Library undertaken as part of my PhD (Sexton, 2016), where I was embedded within the Wellcome Library, and used an auto-ethnographic approach, combined with in-depth interviews with Special Collections staff, to seek to understand perceptions and practice around collection development.

The ethos of collecting at the Wellcome Library can be traced back to the life and outlook of its founder, Sir Henry Wellcome (1853-1936). Henry Wellcome co-founded a successful multinational pharmaceutical company from which he accumulated his personal wealth. He used his accumulating wealth in his own lifetime to fund medical research, and to fulfil his growing passion as a collector of books and historical objects. His collecting interest lay in his fascination with wanting to understand the art and science of healing through time and across cultures. At the time of his death, his personal collection was larger than that of many of Europe's most famous museums (Gould and Faulks, 2007). Although the museum objects collected by Wellcome were transferred to the Science Museum in the 1970s and early 1980s, his book collections were the founding part of the Wellcome Library. Over the years, the Library has been housed in a variety of physical spaces. It has had a sequence of name changes, and has been part of a variety of organizational restructures. However, its history during the later decades of the 20th century has been one of continuing growth and development, with an ongoing acquisitions programme and a focus on expanding use. In 2007, it became part of the newly conceived Wellcome Collection which acts as a free destination which 'seeks to explore the connections between medicine, life and art in the past, present and future; at its heart lies the curiosity that drove Henry Wellcome to amass his diverse collection' (Wellcome Library, 2013a).

In the course of the Wellcome Library's history, expanding the archives and manuscripts collections has been and continues to be a central concern. The establishment of a Contemporary Medical Archives Centre in 1979 to collect records of important 20th-century medical organizations and individuals is testament to the Library's commitment to specifically grow the archive collections. Another significant addition during the 1980s was the purchase of the manuscripts (and about 10 000

printed books) from the Medical Society of London Library (Wellcome Library, 2013a). The archives and manuscripts collection includes nearly 9000 manuscripts, and over 800 archive collections from the United Kingdom and Europe, and the Library sees itself as holding 'the most important collection of manuscripts and archives on the history of medicine in Britain' (Wellcome Library, 2013b). Archives in the collection are concentrated on English-language material from the 20th century, and the collecting policy focuses primarily on material created in Britain and its former colonies. Broadly speaking, the archives include:

- Personal and family papers, correspondence, notebooks and diaries of scientists, GPs and others
- Records of charities, campaigning organisations, and pressure groups
- Records of professional bodies, businesses and research institutions
- The Royal Army Medical Corps Muniment Collection
- The Wellcome Archives, including Henry Wellcome's personal papers, the Wellcome Foundation archives, and records of the Wellcome Historical Medical Museum (Wellcome Library, 2013b).

In seeking to understand the representation of the treatment and experience of the mad, within the archives and manuscripts collections held by the Wellcome Library, I focused on madness from the nineteenth century to the present. In my exploration of the Library's existing archive collections, I found that the most dominant and prevailing archival collection strength, across this time period, is focused around the personal papers of eminent 'psy' experts (psychiatric specialists, psychoanalysts, psychologists and related therapists)<sup>1</sup>. The Library holds a number of prominent archive collections in this area including the personal papers of Melanie Klein (PP/KLE), William Walters Sargant (PP/WWS), Robina Addis (PP/ADD), Ronald Arthur Sandison (PP/SAN) and the art therapist Edward Adamson (PP/ADA). There is also a strong nucleus of collections around professional 'psy' societies and groups including the Group Analytic Society (SA/GAS), the Jungian Umbrella Group (SA/JUG), and the British Psychological Society (PSY/BPS)<sup>2</sup>. The Library also holds the institutional records of a range of private asylums and mental hospitals including Ticehurst Hospital (1787-1975) and Camberwell House Asylum (1847-1853),

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<sup>1</sup> As part of my PhD research I conducted a categorizations exercise of the Wellcome Library's archival representation of the treatment and experience of the mad from the nineteenth century to the present day. I located via their online catalogue and accessions database 128 relevant archive collections representing this theme within this time period, and I found that 91 of those (71%) could be categorized as being the personal papers of 'psy' experts.

<sup>2</sup> The collections referenced throughout this chapter are not cited in the end references. These collections can be searched for on the Wellcome Library catalogue using the collection references giving in the text: <http://wellcomelibrary.org/search-the-catalogues/>

representing another collection strength. Public and voluntary asylums are also represented across the collections mainly from within the personal papers of prominent 'psy' professionals. For example, an extensive body of material relating to Maudsley Hospital can be unearthed across the personal papers of Carlos Paton Blacker (PP/CPB), William Walters Sargant (PP/WWS), Siegmund Heinrich Foulkes (PP/SHF), Rosen Ismond (PP/ROS) and Henry McIlwaine (PP/MCI). This crossfertilization of material across the Wellcome Library's collections in which the personal collections of prominent 'psy' experts also contain material relating to the mental institutions they worked for, and visa versa, unearths a socio-history in and of itself. It is a cross-fertilization that testifies to the networks underpinning the evolution of the 'psy' disciplines. There is also a smaller range of material clustered around the personal papers of campaigners, pressure group members and charity workers active in the mental health field such as Dorothy Silberston (PP/DSI) who was a pivotal member of the National Schizophrenia Fellowship (now Rethink). Here too, the inter-relationships between individuals, groups and institutions can be traced. For example, in collections such as the Robina Addis Papers (PP/ADD) there is material relating to her career as a psychiatric social worker, but also material relating to her role as a pivotal member of the National Institute for Mental Health (later MIND), the World Federation for Mental Health, and other bodies. The third sector within the mental health field is represented not just in individual personal papers, but also through a variety of organizational archives including the archive of the Mental After Care Association (SA/MAC) and the recently acquired archive of the mental health charity MIND (SA/MIN). The library also holds a growing nucleus of material relating to charities concerned with advocating more generally for patient rights, the largest of which is the Patients Association Archive (SA/PAT), where there is a significant body of material concerning mental health patients.

Recognized by the Special Collections staff as areas of notable weakness, are archives that represent and document relatively recent socio-historic shifts in the mental health field. In particular, archive collections relating to the psychiatric consumer/survivor movements that begun to emerge in the 1970s (see Spandler, 2006, p.52-67), and personal archives of psychiatric consumer/survivors, and other individuals with lived experience of mental health. In relation to the latter, two recent acquisitions are indicative of an attempt to shift the socio-historical weight of the collections away from the 'psy' expert and the mental institution, towards archives in which survivors/consumers are representing themselves more autonomously. The first, acquired in 2011 directly from the creator, is the diaries of Pam Maudsley (PP/PMY) which represent a personal documentation of Maudsley's journey through the mental health system and her close relationship with her therapist. The second, acquired between 2014 and 2015, from the family of the now deceased creator, is the Audrey Amiss Archive (PP/AMI). Audrey was a trained artist and also a diagnosed paranoid schizophrenic, and the collection taken in by the Wellcome comprises a significant body of her artwork along with her scrapbooks and additional

personal ephemera. However, both of these collections currently remain closed to the public awaiting cataloguing.

The importance of representation within mainstream institutional archives, and the responsibility that falls on Archivists to be aware of and address potential marginalisations, biases and silences created through their collecting practices relates to power. Foucault's body of writing addresses the power/knowledge nexus and its relationship to truth. Across his accounts of the history of madness (1985), the medical gaze (2003) and the creation of expert knowledge categories from human experience (1972); it is possible to trace how the establishment of a discourse, that acts as a regime of truth, is dependent on the creation of bodies of knowledge. The 'archive' acts as a body of knowledge. As such it is central to the establishment and perpetuation of discourse and is central to regimes of truth. The archive is a means of determining what can be said, and what can be known, and what is considered true. Therefore, representation in the archive matters. Archives establish not just the past, what has been said, but also the present and the future. In Foucauldian terms they can be understood as 'formal systemizations' that give 'functionalist coherence' (Foucault, 1980, p.31) to particular perspectives. They are bodies of knowledge that construct the world. The processes of capturing, fixing and organizing that are inextricably bound into traditional professional understandings of the 'archive' can be understood as a mechanism through which it is possible to objectify those gazed upon, reducing them to categories, data and statistics that can be ordered and controlled. It matters then that individuals with lived experience of madness appear predominately as objects in the archive collections held by the Wellcome. It matters that such individuals exist predominantly in the case notes of medical professionals, and in the columns of asylum admission registers. It matters that this historical pattern of objectification is still an ongoing reality in most of the material the team takes in within the present. It matters because the 'archive' has the power to subjugate:

By subjugated knowledges I mean two things: on the one hand, I am referring to historical contents that have been buried and disguised in a functionalist coherence or formalized systemization... On the other hand, I believe that by subjugated knowledges one should understand something else, something which in a sense is altogether different, namely a whole set of knowledges that have been disqualified as inadequate to the task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity (Foucault, 1980, p.81-82).

Actively seeking to shift the balance to give the subjugated space to speak becomes an imperative because, as Foucault makes clear, it is the re-emergence of the subjugated that enables critique of the status quo:

I also believe that it is through the re-emergence of these low ranking knowledges (such as the psychiatric patient...), and which involve what I would call a popular knowledge (*le savoir des genes*) though it is far from being a general common sense knowledge, but is on the contrary a particular, local, regional knowledge, a differential knowledge incapable of unanimity,

and which owes its force only to the harshness with which it is opposed by everything surrounding it – that it is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work (Foucault, 1980, p.93).

Yet bringing in archives to counter-balance the predominant ‘psy’ narrative *into* an institution like the Wellcome, which has been so long aligned with the dominant medical model of mental illness and treatment is fraught with complexity. Does bringing in counter-narratives into the walls of the institutional archive release that knowledge from subjugation by clothing it with legitimacy? Or does it in fact further subjugate that knowledge under the weight of the dominant narrative?

The first challenge within mainstream settings such as the Wellcome Library, which I explored with the Special Collections staff is the fact that despite recognition of the need to diversify collecting around mental health and madness, an unconscious bias towards the institution and the professional remains difficult to break down.

Interviewees spoke of the ‘seal of institutional approval’ that can be attributed to organizations such as MIND and MENCAP, making the acquisition of their archives an unquestionable given, with archives from grassroots settings and from individuals with lived experience coming up against a higher level of scrutiny around their significance and archival value. This echoes with Bourdieu’s notion of ‘symbolic capital’ which is unquestionably carried by institutions and established categories of professionals who have built up a ‘heritage of commitments and debts of honour, a capital of rights and duties built up in the course of successive generations’ (Bourdieu, 1977, p.178) that serve to legitimate their social standing and their merit. This symbolic capital precedes the perception that their archive material is valuable and sacred, and underscores the assumption that their archives are to be preferred. The weight of this symbolic capital renders the archives of those without such credentials into a marginal position. The value of their material is more readily questionable, more easily discounted as profane. There was recognition within the Special Collections team that the power inherent in the ‘symbolic capital’ embedded in society’s institutions is difficult to circumvent and expose.

My interviews with staff also revealed the extent to which the team shares the same discourse for framing, naming and labelling people and things within the mental health field using the discourse of ‘patient’ and ‘mental illness’. This surfaces one of the major tensions in the collecting of counter-narratives that seek to challenge the dominant medical model of pathology, diagnosis and illness by the Wellcome. There is a gap, a gulf and a void between these counter-narrative and where they are situated in the field of health and medicine, and the situated positioning of the Wellcome Library. The counter-narrative speaks from a position that seeks to challenge the dominant medical model of pathology, and diagnosis, whereas the Wellcome Library is predominantly aligned with this model.

The dominance of the medical framing of mental health is carried into the processing of collections, where the use of Medical Subject Headings (MESH) as indexing entry points, and the organization of medically orientated subject guides into the collections cements the Wellcome’s overarching standpoint. Despite being interested

in collecting alternative views, counter-cultures, subversive positions to the dominant position, the centralization of a medical narrative and frame means that these countercultures actually become subjugated on entry; defined by what they are counter-to; immersed under the dominant frame and its accompanying discourse. Reinforced subjugation is therefore a real danger that is inherent in aligning an oppositional archive under an institutional framework that upholds the norms it seeks to speak against.

It is useful to think of controlled vocabularies such as MESH as a 'symbolic system' that serve three interrelated but distinct functions: cognition, communication and social differentiation (Bourdieu, 1977, p.4-68). As drawn out by Swartz, Bourdieu sees symbolic systems as 'structuring structures' that enable us to understand and order the world that help us to exercise a cognitive function, but they are also 'structured structures' with an internal logic related to codes 'that are deep structural meanings shared by all members of a culture'. (Swartz, 1997, p.83). Conceptual, symbolic systems such as MESH, simultaneously function as instruments of communication and as instruments of knowledge (Bourdieu, 1971, p.295 in Swartz, 1997, p.83). As instruments of both knowledge and communication, symbolic systems such as MESH also operate as instruments of domination, and 'dominant symbolic systems provide integration for dominant groups, distinctions and hierarchies for ranking groups, and legitimation of social ranking by encouraging both dominated and dominating to accept the existing hierarchies of social distinction' (Bourdieu 1971, p.114-115 in Swartz, 1997 p.83). Therefore, symbolic systems such as MESH also fulfil a political function.

There is no straightforward course of action available for disrupting the dominance of the symbolic structures used within the Wellcome Library. There are significant constraints imposed by the infrastructures sitting around the cataloguing system that both locks the team into the use of MESH index terms and enforces a singular top-down hierarchical description of the material, which is difficult to break away from. Furthermore, if the archivist is the one who facilitates the mapping together of related material to make it findable, then he/she will necessarily impose value judgments that shape how the material is categorized, and in so doing will inscribe a worldview over the material that suits the needs of the primary audience carrying with it a privileging effect, re-inscribing the dominant discourse. This can be read as a microcosm of the tension running through mainstream archival work, that when we (as professional archivists) are part of the archival process, we become active shapers of the record, weaving our own situatedness and that of our institution and our primary audiences into the representation of the record. We can push back against this tension, reflect on it, shift its focus, and redress the degrees of control and constraint by enabling others into the process (by working 'with' and not 'on' the subjects in the records, and by finding ways of introducing a multiplicity of perspectives) but even in the most participatory of processes we are always having to negotiate the effects of situation and position which inevitably shape the action and define the possibilities.

Disentangling the Special Collections team's willingness to push back against the privilege, constraint and control bound up in their role as active shapers of the record is delving into complexity. What was articulated strongly at times in the interviews as a hard and rigid position that 'we don't invite' others into our internal processes (coupled with the general sense given across the interviews that the team was relatively content with their level of control over the representation of the record), needs to be balanced with some of my observations of the team at work. A pertinent example that I will draw in here is the team's handling of the Audrey Amiss Archive which was occurring concurrently with the interviews I was conducting, which was indicative of an in-depth collective confrontation of the difficult questions that sit around archival representation in a mental health context, and their particular institutional control of that representation.

The Audrey Amiss collection was offered to the Wellcome Library by Audrey's nephew in 2014. It was accepted as a donation and accessioned in three batches between April 2014 and February 2015. The Wellcome Library's catalogue entry on Audrey states that:

Audrey Amiss was born in 1933 and died in July 2013 just short of 80 years old. She grew up in Sunderland, was spotted as a talented artist as a child and won a scholarship to the Royal Academy School of Art in London. At the age of eighteen Audrey experienced her first episode of mental health problems. It followed soon after the death of her father, to whom she was very close, and this may have been a contributing factor in triggering her illness. She was diagnosed as a paranoid schizophrenic. Throughout her life, she was in and out of mental institutions, many in south London.

I was at the team meeting where the acquisition of the collection was considered. At this meeting several team members strongly argued for the value of the collection as a means to bring 'patient voice' into the archive, advocating that the value of the collection was as a first hand window into a schizophrenic mind. A pivotal shift in the discussion came when the Head of Special Collections began to trouble that notion by introducing more complex underlying ethical concerns into the dialogue. This included raising the issue that as Audrey is no longer alive to give us her opinion, there is a need to think seriously about the ethical implications of placing her archive into the context of a library of health and medicine in relation to the potential this carries to subsume her artwork beneath a narrative that foregrounds her as mentally ill. After the meeting, during a one to one interview, another member of the team reflected:

I found the meeting you sat in last week really interesting. I was really stimulated by the whole meeting. Thinking about the sketch books – until [name] brought up the ethical issues – the institutionalizing of it – I hadn't considered that [pause] I began to feel more uncomfortable with it – the idea that by taking in that collection we are institutionalizing *her* – I still don't really know where I sit about it to be honest. Should we take it? We want to represent patient views [pause] the agreement was we should pursue it further and consider how we would make it accessible to researchers. How

we describe her then becomes an ethical question– that was really interestingly actually.

In the surfacing of these complexities at the accessioning meeting and in the team's reflections on that meeting, I sensed a tangible shift away from a simplistic mantra that 'we have a duty to collect patient voice to balance our collections' towards a deeper reflective engagement with the ethics of archival representation. It was the raising of these ethical tensions, the forcing of them out into the open by the Head of Special Collections that was pivotal in demanding a different response from the team in terms of how they would then act in relation to this collection. The team's commitment to act differently was taken forward through their involvement in a public engagement initiative which took place on 30 April 2015 in the Wellcome Library reading rooms which sought to engage with some of the questions around representing Audrey Amiss' archive ethically. Towards the end of the discussion at that engagement event there was general consensus on a vision of the catalogue entry for the Audrey Amiss collection. The vision was that it should not resemble a formal, standard, single definitive description. Instead the catalogue entry should be premised around the series of ethical questions that can be posed around the curation and interpretation of the collection, and its presence at the Wellcome Library.

This highlights that where mainstream archive institutions seek out collections from communities and individuals in order to re-balance or diversify their collections, or to create a counter-narrative to the dominant discourses threading through their collections there is a need to pay careful attention to the ethics of representation and the ways in which management practices, including description, indexing and presentation can further subjugate.

The ethics of representation, and the tendency for the dominant discourse to subjugate, is part of the reason why for many community archives, distance and separation from the mainstream is desirable. The work of the grassroots Survivor History Group (SHG) is an example of an existing space in which mental health survivors have voice and ownership over their story and their archive. Their ethos is summarized in their manifesto as seeking to:

Highlight the diversity and creativity of the service user/survivor contribution through personal accounts, writings, poetry, art, music, drama, photography, campaigning, speaking influencing...[We intend to] collect, collate and preserve service user/survivor history, make service user/survivor history accessible to all who are interested in or studying mental health, use our history to inform and improve the future, [and] operate as an independent group. The independence of any archive we set up is necessary to prevent limited access to such a resource and to expose the deliberate loss of history – in particular the lived experience of psychiatric system survivors....Our basic founding principle is that service users own their own history (Survivor History Group, 1996).

The SHG can be described as a community archive in the sense that it is a space that has been created, maintained and controlled by community members within their community: by survivors, for survivors 'on their own terms' (Stevens et al, 2010). In this way, the work of the SHG is political and subversive (Flinn et al, 2009) and acts as a direct challenge to the dominant voices presiding over representations of their story. Running through the group's online presentation of their own history and activities is a strong sense of the ways in which their history has suffered when written in the hands of others. The group sees their history as an opposition to narrative written by non-survivors (mainly academics). It is a vehicle that simultaneously points to, and redresses, the lack of acknowledgement by the academic community of the existence of survivor-led historical research.

Further, insight into survivor perspectives on the importance of survivor control over survivor history can be traced through the SHG's documentation of the 750th anniversary of Bedlam. This anniversary took place in 1997, and was marked by the creation of an institutionally curated exhibition on the hospital's history, exhibited at the Museum of London. Peter Beresford offers an insightful critique of the exhibition, first published in *OpenMind* in May/June 1998, reproduced by the SHG in their online archive. His critique is woven into a powerful rhetoric around the necessity of survivors controlling their own history:

We might have expected that a history that from its earliest days reveals a familiar catalogue of inquiries, scandals, abuse and inhumanity would be approached with the same sadness and solemnity as any other past inhumanity or oppression. Instead it has become an opportunity, complete with commemorative mug, keyring, paper clip and teeshirt, for reinforcing professional pride and the brand identity of a medical product which by its users accounts has more to correct than to be proud of. Perhaps most disturbing of all has been its associated exhibition. This is presented in classic modernist terms of centuries of progress, culminating in modern psychiatry and the Maudsley Hospital. It is made all the worse because it is given the respectability of being housed in the Museum of London, which generally shows a sensitivity to issues of difference and discrimination. The current psychiatric orthodoxy that 'genes contribute to most mental illness' is presented as fact. The experience of thousands of inmates is reduced to a handful of indecipherable photographs posed in hospital wards and grounds, and select biographies of the famous and curious few... If mental health service users/survivors are to take charge of our future, then we must regain control of our past. That past, at both individual and collective levels, has largely been appropriated, denied, controlled and reinterpreted by other powerful interests, notably medical professionals, the state, politicians, charitable organizations and the media. This has been destructive to all our futures. In recent years, the survivors' movement has begun to challenge this

rewriting of our history (Beresford, 1998 reproduced in Survivor History Group, 1998).

The strength of feeling associated with the argument around the unique difference that independently created survivor history offers in comparison to other versions of the story, and the necessity of creating this 'different' history, along with the strong notion that such a history created by survivors can also be best cared for, most nurtured and made most widely available through independence resonates strongly with the motivations, positions, values and beliefs found in many other grass-roots community archive contexts (Flinn et al, 2009). Creating, collecting and curating embodies 'the symbolic power to order knowledge, to rank, classify and arrange, and to give meaning to objects and things, through the imposition of interpretative schemas, scholarship and the authority of connoisseurship' (Hall, 2005, p.24). Therefore, in order to hold symbolic power, survivor groups need to be in control of the archival process.

In conclusion, institutional archives such as the Wellcome Library, that look to enrich their collections with counter-narratives that can disrupt or re-balance dominant discourses running through their holdings must carefully engage with the ethics of representation and consider the danger of re-inscribing the dominant narrative through process of subjugation in how that material is processed, described, interpreted and made available to the public. Institutions with the resources to do so should consider approaches to support and facilitate the archiving process in grassroots and community settings without seeking to bring those archives into the walls of the institution. Where archives that represent counter-narratives do come into the walls of the mainstream, the most ethical approaches to the management, processing and curation of those collections involve a sharing authority, and process of co-production. If sharing authority runs counter to the ethos of the institution, then attempts to collect counter-narratives are likely to fall foul of becoming a damaging appropriation of the history and culture represented within the collection rather than a diversification and rebalancing of the narratives that the institution holds.

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