Mental Health Records: Who Controls the Past?

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Mental health records are seen to be a particularly sensitive archive and some see the preservation of such records as contrary to the maintenance of doctor/patient confidentiality. Part of their particular 'sensitivity' I would suggest lies in the stigma that has, historically, been attached to mental illness; a stigma that the television campaign launched in 2000, 'Like Minds, Like Mine' attempts to overcome.[1] This campaign resulted from the 1996 Mason Inquiry which recommended action be taken to reduce the stigma and discrimination experienced by sufferers from mental health problems.

Over the years I have worked on the Seacliff Asylum archive, currently held at the Dunedin Branch of Archives New Zealand, Te Rua Mahara o te Kāwanatanga. These are the records of, in G. Thomas Couser's words, 'vulnerable subjects': people unable to represent themselves because of mental illness.[2] Access to the patient records less than one hundred years old in this collection is restricted and an application for access must be made to the Otago District Health Board. Here I want to discuss some of the questions I have faced using these records over time.

When I first began working on the Seacliff archive in the late 1980s, it was held by the Hocken Library and I applied for access to the Medical Superintendent of Cherry Farm, the successor hospital to Seacliff, which remained open at that time but which closed in 1992. The Medical Superintendent was keen to have the history of mental health treatment recorded. As part of the agreement for access, I undertook to fictionalize all the patient names in order to protect confidentiality.[3] I entitled one article, about a young woman who had an invasive and disturbing 'unsexing' operation 'Annemarie Anon' imagining that the surname made the fictional device plain. To my surprise, apparently some readers took this to be the young woman's real name and enquired at the archives to see her file.[4] I published two further articles using the case files and fictionalizing names and, to date, no relative has complained.[5] Indeed, the opposite has been the case. A number of people, wishing to know the fate of their kin committed to asylums, have written for advice about

how to gain access to the relevant files or to ask if I can find out what happened to their relatives.

By the time Jane Thomson and I completed editing a collection of essays largely based on the Seacliff archive, *'Unfortunate Folk': Essays on Mental Health Treatment 1863-1992*,[6] the collection had been rehoused at the Dunedin Regional office of Archives New Zealand. I wanted to give the patients a face, and I was delighted that we received permission from the Patient Affairs Officer (of what was then named HealthCare Otago Ltd) to use photographs of four patients to illustrate the text. One of those, of a 44-year-old married woman with a penetrating gaze, was chosen for the cover. This photograph, and the two further ones of the same woman in the file, had always intrigued me. The Medical Superintendent of the Asylum in the 1890s, Dr Frederic Truby King, recorded in the case notes that she had said to him 'I suppose you want a picture of a madwoman. I'd better stick some straw in my hair and make faces'.[7]

In 2010 I returned to that series of photographs when I was asked to write an essay about photography in the asylum. I knew there was a sequence of three photographs. This time I determined to ask permission to name the 44-year-old woman so that she could own her story. It had become clear that her committal to Seacliff was a matter of public record (open to all through *Papers Past*) since her divorce on the grounds of 'lunacy' (with evidence given by Truby King that there was no chance of Mrs Beckett's recovery) was in the *Evening Post* newspaper on 29 June 1910. Her committal to Seacliff was a matter of public note in 1910 since her divorce was one of the early ones to be enacted on the new grounds of 'lunacy' introduced in 1908.

The Otago District Health Board declined my request to reproduce the three photographs and to use Johanna Beckett's name. The decision was justified on the grounds of upholding the Board's 'responsibility to protect the privacy of information belonging to our clients and to act in our clients, including deceased clients, best interests'.[8] In support of this stance, the letter cited Rule 10, 'Limits on Use of Health Information of the Health Privacy Code 1994.' The Board's representative speculated that 'It is highly likely that Johanna Beckett has surviving relatives and that these surviving relatives would not authorize the use of her personal information in a publication.' I was given permission to reproduce the photograph that had been used earlier. I was also given the opportunity to request a review of the decision.

Since I had first used the Seacliff Archive, the issue of privacy had come to the fore and it was this issue that led to denial of access. There

was a new cadre of people involved in the decision-making and they had the privacy concerns of current patients foremost in their minds rather than the historical study I was undertaking. Unlike the former Medical Superintendent of Cherry Farm who had an interest in the history of mental health, these individuals were concerned about current patients and with the legal implications of their actions.

The denial of access led me to ask who could determine a deceased person's 'best interests'? Johanna Beckett had died over 90 years ago in 1918 in the Seacliff Asylum. She had had little control over the events of her life and I considered she may well have liked her story to be told. When I have interviewed older women they have often said that they've done nothing of significance, imagining that history is the preserve of those of importance in the public sphere. They are pleased that someone is interested in the 'everyday' texture of their lives. Feminist historians have done a great deal to rescue women's lives from, in E.P. Thompson's words, the 'enormous condescension of posterity'.[9] Johanna Beckett, married to a struggling Waimumu miner in rural Southland, had a life of suffering but Truby King found her to be sharp and 'witty'. Since no relative had approached me since the use of her photograph on the cover of a book over nine years since it had been published, I felt it unreasonable to assume they might take offence if her story was recounted in 2010. I also knew from the Births Deaths and Marriages records that Johanna died childless in 1918 and therefore any relatives that did exist had to be distant.

Perhaps the most important part of my request for a review of the decision to deny access was that identified by an expert in New Zealand's Privacy Law. He pointed out that Rule 10(2) of the Health Information Privacy Code stated 'This rule does not apply to health information obtained before 1 July 1993.' It could hardly, therefore, apply to information obtained in the 1890s. Any legal concerns were, therefore, demonstrably unfounded. In the event, the Chief Medical Officer granted permission to use both the photographs and Johanna Beckett's name.

When I supplied a copy of the paper I had written along with my request for review, the Patient Affairs Officer offered her congratulations on my article commenting that 'it allows people today to have insight into the standards and treatment of patients in the past'.[10] This seemed to me to be the crucial role of the historian. I noted in my request for a review that part of my purpose was to humanize those who have been cared for by New Zealand's mental health system in the past, empowering them by giving them a voice with which they may speak to the present.

I noted that it was difficult to discern at this great distance in time what would be in Johanna Beckett's 'best interests', but I suspected that giving her a voice to speak to those in the present was no less in her 'best interests' than keeping her nameless and hidden from view for all of eternity. The piece was published as 'The asylum lens: photographs in the Seacliff Asylum case files.'[11]

One psychiatrist felt unsure of the claim I was making for accessibility and asked me to speak at a public forum about the issues involved. Health professionals, of course, must protect the confidentiality of their patients. Patients need reassurance that whatever they share with health professionals will remain private; otherwise, they may not seek assistance. Historians have traditionally agreed to protect confidentiality but this requirement does not apply to material (in the Otago case) to records over 100 years old. So there is the question of how does the passing of years work to diminish privacy? One cannot, for example, be sued for defamation of a dead person. But the slight possibility exists that, if what you say about them reflects badly on their family or friends, you could be found guilty of defaming the latter.[12] The implication might be that, by revealing a mental health problem, relatives will suffer by association, but this is only likely if mental health problems are subject to stigma. What sort of ethical obligations attend to the use of old patient records? Does a different standard apply than to old school records, for example, or criminal records?

The original denial of access led me to observe the differing conditions that are placed on such archives throughout New Zealand. The Otago District Health Board appeared to be unusual at holding a 100 year restriction. Recently one of my students has faced delays to her work because of access issues. One problem lies in the fact that the bound casebooks from the Seacliff Asylum contain information across the years so it is difficult for staff to ensure that students can ONLY access material that is 100 years old. If a 75 year rule was applied, this difficulty would cease. The mental hospital records in the Auckland Branch of Archives New Zealand are, as I understand it, completely open-access after 75 years. Therefore files in Auckland can be requested by anybody whereas in Otago, researchers have to request access (which involves consequent delays) which is sometimes denied. The variability of the interpretation of access requirements, with consequent appeals, acts as a barrier to research.

In 2009, I worked on a project in the Osler Library at McGill University in Canada. The library held a rich archive of letters from two sisters,

Maude and Alice Abbott to their cousins. Maude Abbott went to Europe to pursue postgraduate training in medicine in the 1890s accompanied on her journey by her older sister, Alice. The letters revealed the tragic story of Alice's mental breakdown and Maude's desperate attempts to look after her. Eventually, Alice was placed, for a time, in the Gartnavel Asylum in Glasgow. I contacted the National Health Service Greater Glasgow and Clyde Archives by email about the possibility of accessing Alice's records and was astonished to be sent, in return, a digital copy of Alice Abbott's case file. This enabled me to complete a paper about the care which family members sought to provide for their mentally ill relatives.[13]

The ease of access to these records led me to seek advice from Alistair Tough, NHS Greater Glasgow and Clyde Board Archivist, about the standard provisions in the United Kingdom and he replied as follows:

> 'We apply a 75 year rule to the clinical records of adults (and a 100 year rule to the clinical records of children) to comply with the UK's Data Protection Act which requires that we do not disclose sensitive personal data of living data subjects without their consent.'[14]

This is more liberal that the current regime of the Southern District Health Board. I subsequently wrote to the Board to see if they would review their policy but they wish to uphold the status quo. One particular difficulty that I see in the current access policy is that the decision is made by people with no archival or historical training. They are people concerned with issues in the present and hence not really cognizant, in making their decision, of the important role that historical research can play.

Thinking about this issue raised the question, why keep archives if the stories of individuals are to be buried for perhaps a century? I found the answers provided by the Northern Ireland Public Record Office particularly helpful and they are reproduced here.[15]

> **Why do we keep archives?**
> **To learn about the past**
>
> If you want to write a history book, find out about something that happened in the past or about a character in history, then you would have to look at the archives, analyse the evidence and decide what the evidence is telling you.
>
> Since historians can't always question the witnesses who lived at the time, archives often provide the only source of evidence which can be used to inform us about the past.

To help us understand who we are and how we came to be the way we are – both as a community and as individuals.

Without knowing what has shaped our community, our country and us as individuals, we have a lesser sense of identity.

Without a documented heritage in the form of archives, our knowledge of communities, families and the built environment would be the poorer.

For evidential reasons

Archives have long been kept as evidence, to be used in a court of law if necessary, as proof of rights and entitlements.

For example:

- wills are kept as proof of inheritance
- title deeds as proof of ownership of land or of mineral rights
- registers of births, marriages and deaths are kept as evidence of our identity and are needed for a whole range of purposes from passports to pensions
- maps and plans might be used to identify contaminated land or old mines that could cause building subsidence.

For education and learning

Archives can also provide a stimulating and exciting learning environment – for schools, universities and for the lifelong learner. They help to enrich and enhance teaching at all levels.

For personal reasons that affect individuals' lives today

Access to archives is often needed for personal reasons, for example, if one is trying to establish the circumstances surrounding the death of a loved one or for tracing missing members of a family.

Contributes to accountable government

Citizens have a general right of access to information about the activities carried out by government organisations acting on their behalf. Government records whether of central government, local government or of other public bodies are vital for democratic accountability. Without archives that document the decisions of government and how those decisions were made, there could be no public scrutiny of government.

Access to mental health records may well be required for personal reasons as when relatives want to learn the fate of a family member committed to an asylum. But for the historian, there is a larger aim and that is one of accountability. Such archives allow historians to probe how society has treated its most vulnerable members. Without access to the records of the vulnerable we would not have, for example, Bronwyn

Dalley's excellent history of child welfare, *Family Matters: Child Welfare in Twentieth Century New Zealand* (Auckland: Auckland University Press, 1998).

I have tried to think through the issues of harm: what 'harm' will ensue if a forebear's mental illness is revealed? My argument would be that making mental illness 'ordinary' through historical analysis, making it clear that anyone might suffer in this way, helps to reduce stigma in the way the John Kirwan advertisements succeeded in doing.[16] The 'Like Minds, Like Mine' campaign has been demonstrably successful in normalising mental illness as an illness like any other. People are now much more likely to believe that mental illness is something that can happen to anyone and that people with mental illness can still lead a normal life.[17] Historical studies can contribute to this normalisation project by revealing how people are subject to the vicissitudes of life and how society has responded to their variable needs. Such studies help to throw our present-day policies into relief.

Historians have a professional responsibility to treat records with care and circumspection, alive to the distress they might cause. Historical training requires historians to ask meaningful research questions beyond being voyeuristic. In the case of mental health, historians can act as 'myth-busters' and, by providing context, illuminate how institutions worked in the past. I have, for example, often been told that women who had illegitimate children were routinely sent to Seacliff. Yet in my sampling of the files from 1890-1910, the only woman I found who fit that description had actually written to Truby King and asked him to take her in because her Southland community had rejected her. She wrote to King because he was well-known for his campaign for saving babies, through his founding of the Plunket Society.[18] The other 'myth' is a convenient kind of distancing: that somebody else was responsible for bleak conditions in asylums. Yet when one reads the letters of the asylum superintendent to central government pleading for more baths to provide better conditions for the patients, it is clear that it is our forebears – the taxpayers – who did not want to provide the funding for such services.

Mental health archives can tell us how conditions were understood by officials, doctors and sometimes by patients. The trail of statutory papers that accompanied committal demonstrate the State's commitment to accountability. People were not to be denied their liberty without good cause: hence constables, family members, magistrates and local doctors were all called upon to record why someone should be admitted to the asylum. This context allows us to see that mental illness placed

real strains upon families who sought resolution by seeking care for their disturbed relatives.

Historical study allows us to ask questions such as what resources were provided for patients and staff? Which populations were at risk of committal? When and why did family members decide that committal of a loved one was the best course of action? In my study of women and madness based on the Seacliff files, I saw the multiple ways that the asylum was used in the late nineteenth and early twentieth centuries. Women might receive convalescent care there – meals and a respite from domestic work – and re-emerge 'cured' after a stay of a few months. They might have drunken husbands committed (with a clergyman's help) in order for them to 'dry out'. Then there were those in great distress, with mania, who were subject to delusions and tore their clothes and required the kind of surveillance to prevent self-harm that only the asylum offered (and even then, suicides did occur). I also learned of the treatment of those outside of the asylum at the hands of their supposed 'loved ones'. Johanna Beckett's husband, according to the local constable, beat her. Careful use of the records enables us to follow people from their life in the community into the asylum and out again. They allow us to see that life outside, in impoverished and hostile circumstances, might not be better than life inside, as is so often freely imagined.

In the Seacliff archive I see a mass of captured biographies that allow us some insight into the lives of ordinary people who might otherwise never enter the written record: domestic servants, labourers, clerks and hotel keepers rarely had an opportunity to tell their stories. There is no way of knowing if they would want historians to do the telling. A key concern for historians is not to misrepresent these stories but to be alive to the multiple interpretations that might exist. Perhaps we could consider that the passage of time makes it in the current generation's 'best interests' to be informed by the past experiences of deceased individuals. As psychotherapist and historian Sally Swartz writes 'Histories of insanity bring to attention the dilemmas universally confronted not only by governments and communities, but also by families ...'. She continues

> The lessons of history have much to offer on the relationship between mental health, cultural difference and institutional responses to mental illness. Institutional landscapes may shift over the years, but many of the challenges, triumphs and intractable sorrows of nineteenth century asylum doctors and patients are easily recognizable to today's clinicians. The measured historical eye of the problem is comforting.[19]

Questions of access for historians are, I suggest, about much more than legal liability under privacy codes. They are about the possibility of contributing to a wider collective understanding of intractable social problems.

Endnotes

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18. Brookes, 'Women and Madness', p. 139-40.
19. Sally Swartz, 'Madness and Method: Approaches to the history of Mental Illness,' in *PINS* 37 (2009), 73.