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Life stories, intellectual disability, cultural heritage and ethics: dilemmas in researching and (re)presenting accounts from the Scottish Highlands

Karrie Marshall and Liz Tilley

Abstract

This article reflects on the ethical dilemmas involved in undertaking research on the history of institutional and community intellectual disability services between 1966 and 2009 in a tight-knit community in Scotland, through the *In Our Own Voices: Leaving New Craigs* hospitals' story project. The accounts collected include painful memories of oppressive practice as well as fond recollections of community spirit, kindness and 'good' staff. However, the research stirred up sensitive issues amongst the community that left the researcher facing a number of challenges. In this article the authors will reflect on the ethics of investigating, confronting and disseminating difficult histories.

Introduction

There is a growing interest and commitment to exploring and recording community histories and the heritage of traditionally marginalized groups in the UK, including people with intellectual disabilities (Mitchell et al, 2006; Dias et al, 2011). Whilst such a development is to be welcomed, this article reflects on some of the complex ethical and methodological issues that may emerge in such studies, particularly when those marginalized groups are based in 'tight knit' communities. In the context of this project, undertaking research in a culture which valued privacy and discretion created a genuine sense of fear and hostility amongst participants that the first author, Karrie Marshall, was only partly prepared for. This had to be weighed against the importance of meeting the project objectives, disseminating the stories, and giving voice to people with intellectual disabilities, whose experiences and perspectives have been neglected and discredited for so long in public discourse (Munford et al 2008).

Background to the research project

The first dedicated intellectual disability hospital for the Highlands and Islands (Craig Phadrig) opened in Inverness, Scotland in 1969, with 241 beds, at a time when the de-humanising effects of institutionalization were being widely recognised (Goffman 1961; Nirje 1969). The facilities far exceeded the accommodation of the psychiatric hospital (Craig Dunain) where children and adults with intellectual disabilities had previously lived. However, the next three decades saw movement from hospital to community care throughout the UK, influenced by reports, legislation, and theoretical ideas (Better Services for the Mentally Handicapped white paper 1971; Wolfensberger 1972; Caring for People white paper 1989; and the NHS and Community Care Act (Scotland) 1990), and by the mid 1990s, plans were afoot to close Craig Phadrig Hospital.

To prepare for the closure, a re-provisioning group comprising the NHS and Local Council, advocates, nurses, occupational therapists and community staff was set up to oversee the successful move of people into community care. Placement was difficult for approximately 40 people with complex intellectual disabilities, and so small units were built in the grounds of the new NHS psychiatric hospital ('New Craigs') to house them, where the remaining Craig Phadrig staff could continue caring for people they had known for as long as 30 years. Hospital staff later explained they had not anticipated further moves, even when in 2000 'The Same As You?' Scottish Executive white paper stipulated the closure of all long-stay hospitals (and units) for people with intellectual disabilities in Scotland by 2005. In 2006, a charitable organisation from the central belt of Scotland, with 25 years' experience of specialist support, were in negotiations for providing a new Highland based community care service for the remaining individuals. In 2007 the charity was awarded a 3-year contract and by 2008 they were in an intense period of staff recruitment.

The story project – aims and methods

At this stage of rapid growth, the charitable organisation, which had a strong track record in promoting arts for communication, was granted a Heritage Lottery award to employ a story gatherer. The purpose of the *In our Own Voices* story project was to record, preserve and share the historical heritage and culture of the 35 people with intellectual disabilities being supported by the charity. The first author joined the charity (who was the research commissioning body) in 2008 as the story gatherer, 8 years after Craig Phadrig had closed.

The story project's aims were:

1. To support as many of the 35 individuals as possible with multiple and complex needs living in intellectual disability units within New Craigs to explore their cultural heritage and tell their life stories.
2. To produce personal life story DVDs for each individual as a record of his or her life.
3. To provide a public record or booklet of the stories to preserve the cultural heritage of people who lived in long stay intellectual disability hospitals.
4. To hold an event / exhibition to inform the public about the heritage project and disseminate the work.

At an early stage of the research, it was acknowledged that the project would also seek the views and memories of other key people in the lives of these individuals – including family members and staff. Recruitment of participants began through information posters, personal letters, newsletters, a press release and staff inductions, inviting people to information sessions or to make contact with the story gatherer. A schedule was made for 1:1 interviews; story groups; video recordings; visiting service users; and archive research.

Due to the anticipated methodological and ethical issues likely to arise during the project, the first author secured the involvement of an

independent supervisor in Nottingham (a retired care and counselling practitioner). She also liaised with the Scottish Consortium for Learning Disability, the commissioning body's arts and well-being team, and members of the Open University's Social History of Learning Disability Research Group. It was decided that the data would be analysed and presented thematically, with stories grouped under the following themes: personal space, personal care, personal belongings, personal clothes, mealtimes, medication and treatment, social activities, relationships, occupations, therapies and community care. These codes were able to accommodate stories or narratives from a range of contributors. If the first author heard a story three times from different sources, it was included. While this did not prove the stories were 'true', it highlighted that they were valid descriptions of a shared and interwoven heritage.

Whilst oral history has been long acknowledged as a powerful means of revealing previously hidden histories and giving voice to those excluded from society (Portelli 2003; Thompson 2009; Walmsley and Atkinson 2000), its challenges must also be acknowledged. Jessee (2011) has written about the theoretical, methodological and ethical limitations of oral history in the context of particularly 'politicized' research sites. Whilst intellectual disability services in the Highlands do not necessarily represent the 'extreme' cases of oral history research that Jessee was reflecting on, it soon became clear that the research site contained painful memories and complex emotions. Feelings of pride, shame, anger and fear were issues that had to be continually negotiated throughout the entire project. However, as Rolph and Atkinson (2010) have argued, it is important for researchers to acknowledge and reflect on the centrality of emotions in intellectual disability research, as they are often integral to an analysis of findings. The remainder of the paper is an account of the ethical dilemmas that arose throughout (and beyond) the life of the project, and how the first author attempted to manage and address these in practice.

Researching the life stories

From the project outset, the first author acknowledged the potential challenges involved in asking personal questions about the life experiences of people with intellectual disabilities who were traditionally considered unable to speak for themselves (Fido and Potts 1989), and recording their heritage and culture about life in long-stay institutions within a wider culture used to maintaining silence on private matters. In his review of Burnett's book about the Scottish Highlands, Blaikie (2012, online article) sums up an understanding of Highland Culture as 'partly an invented tradition imposed from without and partly indigenous cultural defence'. Indeed, concerns were soon raised by potential participants about personal stories being made public. This was an ethical dilemma that had been preempted at initial discussions with the commissioning body. The first priority was therefore to establish a set of ethical guidelines through the production of information and consent sheets. Conversations with the commissioning body and the Oral History Society supported the design of a confidentiality statement and consent form for potential participants or their guardians to sign. Options for personal life-story work and personal DVD records included being digitally recorded, maintaining privacy of the story for personal, family and/or direct carer's use, and opportunities to withdraw consent at any time during the project. Although the confidentiality statement was useful in terms of reassuring potential participants and offering them flexibility, it did not solve the question of how to involve or gain informed consent from people with high support needs, who were integral to the project.

Involving people with high support needs: communication and informed consent

Of the 35 people identified by the commissioning body, the majority did not use verbal language, nor a formally recognised sign language. Researching their life stories required creative approaches and presented ethical dilemmas about interpreting behaviours or contributions. Story-boxes were created, and physical objects collected (ornaments representing

pets or favourite activities; preferred food labels; family and hospital photographs) to signify the individual's past heritage and culture or preferences. Whilst historical accounts were difficult to elicit, it was possible to observe how people engaged with each other and the objects, such as pretending to pour tea and shouting 'No! Just one! Just one!'. The artwork included collages using wallpaper and photographs of the old hospital. One man drew himself as a circle 'me' in a square, 'my new home' and added some ticks. However, the first author was wary of offering concrete interpretations.

Factual information about dates of admission and medical history could be gathered from individual care plans. An oral history questionnaire was designed to elicit qualitative personal and social histories about memories of hospital life, such as concerts, gardens, pets, friends, industrial therapy, favourite places, meals, rules, difficulties and feelings about the closure. Informal discussions in groups and one-to-one meetings were either videoed, sound recorded or written up immediately following the session, depending on consents. The first author worked closely with the commissioning body's video production officer for the life-story DVD work with 12 participants and their guardians. Historical life-story accounts were often sketchy, so some DVDs portrayed the service user's journey from hospital to community care (a significant cultural change).

Ledger's (2012) consent protocol for involving people who do not use speech or written language to communicate was adopted. This promotes the use of support circles (family, advocates, care staff), whose knowledge of the person, and observation of their responses can inform whether or not the individual is comfortable with participating in the project. The circle monitors the individual during and after every session with the researcher. Any distress or negative response to the activities is deemed as declining consent to participate.

Even with such a protocol in place, not every person had a living relative, the new staff did not always know the service users, and social services

care managers and NHS staff spoke of feeling professionally compromised when asked to help out with the life-story information. This resulted in 7 people not being included for recorded personal histories, although they were still invited to art and story-group activities.

Barriers to participation

It soon became apparent that there was a deep sense of loss experienced by the remaining NHS staff with the planned moves to the community.

Community care had been talked about for over ten years, but without action for 'their patients'. Now the changes were real, there were feelings of distress and anger, which seemed to translate into non-engagement with the story project. Staff mentioned their reluctance to work with an unknown organisation, and questioned the motives of the charity for undertaking the story project. The researcher was not regarded as neutral. The charity had employed the first author as a story gatherer, but the nature of the project was research. To legitimately continue the story project the first author needed to establish herself as a more independent player, free from the constraints of a commissioning body employee.

Preston-Shoot et al (2008) have discussed the interface of commissioning processes and research, highlighting that the objectives and responsibilities of commissioners during research projects need to be addressed more explicitly. They argue that the political, organisational, structural, financial and relational context of the research is frequently neglected in initial discussions between commissioners and researchers. Whilst the first author believed the commissioning organisation's project objectives were valid and well-intentioned, her links to them were confusing for participants, who perceived the organisation primarily as a service provider and employer.

The first author discussed these concerns with the commissioning body who understood the dilemma and agreed that she could leave the job, taking up the story project on a free-lance basis. Letters were sent explaining this position to service users, relatives, new staff and NHS staff.

The project eventually secured the participation and inclusion of 10 relatives, 23 people with intellectual disabilities from New Craigs and 40 staff of the commissioning body; plus 22 more people with intellectual disabilities living at home or in community group homes; 2 doctors; and a further 55 staff (ex-nurses, occupational therapists, social services, estates staff, advocates and visitors to the hospitals such as the fire brigade or friends).

Providing a public record and disseminating the findings

Maintaining confidentiality in a shared and social history

The final stages of the project were focused on creating a public record and disseminating the information. The issue of ‘going public’ caused alarm for people concerned about being identified. The first author was able to offer reassurance about finding ways to re-present shared historical heritage and culture of people with intellectual disabilities by focusing on the *social history* from a variety of sources, including archives and the voices of a wider network of people.

For example, the first author was invited to other care services where people with intellectual disabilities lived, having moved out of hospital in the 1980s and early 1990s. People wanted to tell their stories. But they wanted to do so anonymously. Staff and ex-staff offered accounts of their own experiences, although there was still a fear about being exposed. The Highland hospitals had employed generations of families. People did not want others to know they had met with the first author, posing another dilemma, as in group situations people would act as though they had never seen her before. In addition, potential participants would make arrangements to meet the first author, and then fail to turn up. All these occurrences were regarded as a measure of how difficult people found the process.

Most contributors were reluctant to sign any consent forms, declined digital recordings and wanted complete anonymity. The first author therefore faced a dilemma about whether or not these people's stories should be included in the research. But as it had taken over a year for people to come forward, it seemed important to honour their stories by at least listening to them. The questionnaire was used regularly, but sometimes people had a specific narrative they wanted to express. People occasionally made contributions 'off the record', meaning that the researcher was not permitted to take any notes. Some stories could be verified through photographs or records or repeated separate accounts. The first author heard many accounts of similar experiences, such as the involvement of everyone in annual concerts; the strong community spirit; the dreaded paraldehyde injections; what happened if someone was late for a meal or ran away; and many tales of survival.

One or two staff said they knew the first author had met with some ex-patients and suggested they were known to make up stories, advising that not everything should be believed. Other staff expressed their concerns that the project was trying to uncover horror stories. This was fuelled when the local paper ran a headline about the project 'delving into the hospitals' past.' The first author received two anonymous phone calls telling her to stop the story project. Some people withdrew their consent to participate; yet others offered their permission to go public. These difficult issues were worked through and addressed via the researcher's supervisory arrangements.

Stories of oppression and alleged abuse

Whilst there were many stories told of friendship and care, the research also revealed a number of traumatic experiences, common to institutionalized care. Another ethical issue that arose was therefore dealing with stories of alleged abuse. The first author used the British Association for Counselling and Psychotherapy ethical framework, having trained as a

person-centred counsellor many years before. At pre-arranged interviews she would run through the consent form to discuss the boundaries of confidentiality (even if the person did not wish to sign the form), and explain that these issues may need to be discussed (anonymously and confidentially) with her project supervisor. When people indicated they had witnessed or experienced abuse, the first author would listen and explore options for seeking further help from national organisations or their own support network. Telephone calls were received from people who felt great shame at having taken part in acts of routine inhumane practices. One older man phoned in tears because he needed to tell someone what he had witnessed so he could die in peace.

Some painful stories were likely to cause great upset to relatives, staff, service users and the general public. People who had lived and worked in the hospitals had shared their stories, many for the first time. The researcher felt a responsibility to protect the story-tellers and the potential audiences, whilst also dealing with personal feelings of anger and distress after hearing some of the stories. The researcher reflected upon whether her own hesitancy to publicise some of the stories might also make her an oppressor. That was a moment of revelation which resulted in the first author immediately contacting People First Highland (a self-advocacy group of people who use intellectual disability services) for advice. They were asked their views about whether all the stories should be made public. There was a long silence. Then one by one people stood up and said the stories must be told. One person commented: *'There was good, and there was bad. If people get upset, they should know it didn't happen to them, it happened to us... and if they know the truth, they will make sure it never happens again.'*

This clarity enabled the first author to continue, as members of People First had taken the responsibility for stories about their historical heritage and culture to be made public, whilst protecting anonymity. Whilst it may be relevant in some research studies to consider the appropriateness of employing anonymity as an ethical principle (Tilley and Woodthorpe,

2011), there was no question that the narratives in this project needed to be made anonymous. The stories combined with archived reports showed the long stay hospitals were a complex mix of compassion, tragedy and comedy.

Public reflections at the project end

152 people in total contributed to the story project. The project culminated in a public exhibition of history spanning New Craigs, Craig Phadrig and Craig Dunain hospitals. People who had shared their stories, plus care and support organisations, medical staff and student nurses attended the exhibition. A reflective space enabled people to write their thoughts or wishes. These messages became exchanges between people who had lived in the hospitals and people who had worked there, with recognition and apologies for some of the old ways of caring. There was also hope that we continue listening to people and promoting better services.

There were three messages of apology:

'I wish that never again will we treat people in such an inhumane manner, albeit that it just seemed like the thing to do at the time.'

'It brought tears to remember the indifference and cruelty. It was a harsh life. I did my best.'

'I worked there. We had some good times but sometimes it wasn't. I am sorry'.

Conclusion

The-hospitals' story project was a journey full of ethical dilemmas, and needed a flexible, responsive approach to negotiate the challenges that arose. The project may have run more smoothly had the hospital to community transition already taken place, but this would have made access to many of the ex-staff more difficult. This research project was not

(despite participants' initial anxieties) about one set of stories trumping another. The project was committed to presenting an holistic account of the past, revealing a range of experiences. This meant acknowledging and including narratives that may have appeared contradictory and which stood in tension with others. Greenop (2010) argues that researchers must be accountable and responsible for people's narratives from beginning to end. Good data gathering is not only about following 'correct' procedures, but requires the wisdom to negotiate and acknowledge the limitations of the act of representing participants' accounts:

It is the responsibility of the ethical researcher to make sure that their voices, however 'unacceptable' they may be, can at least be heard. Qualitative research may not bring about institutional change either but at the very least it can enable a dialogue with those in positions of power and authority such as service providers and policy makers. It is, however, no easy task to speak on behalf of participants, not least because the re-rendering of their accounts into a single coherent narrative acceptable to one necessarily entails 'reducing' the other, but clearly no one is fully revealed (or understood) in research. (Greenop 2010: p.309)

This research project raised ethical concerns that - at times - stood at the forefront of the project, threatening to overshadow the research aims entirely. These concerns continued throughout the project's duration, and continue today as the first author reflects on how to disseminate the findings in a way that stays true to the research whilst minimizing distress and disruption for those who participated. This article has drawn attention not only to the intellectual ramifications of these ethical dilemmas, but also their emotional impact on the researcher, both personally and professionally. Whilst the first author was able to draw upon her previous experience in counselling to navigate some of these experiences, her reflections highlight the centrality of these issues to the research process, an area so often neglected in written accounts that are published in peer reviewed journals.

The abandoning of consent forms for some participants during the research process; meeting people informally and ‘off-the-record’; and deciding if/when to anonymise (particularly complex when creating a so-called public record of events) in this project are all examples of the delicate balancing act facing researchers tasked with investigating historically closed communities whilst aiming to conduct research that is ethically and methodologically rigorous. In addition, the first author was confronted with negotiating a wall of silence at the project outset and, at times, open hostility. She had to manage the local media and the ongoing fears and anxieties bound up with revealing stories rooted in a difficult, and sometimes traumatic, past. Ultimately however, she worked hard to create an environment of no-blame that allowed people to begin a process of truth and reconciliation. It is our view that researchers must be given more opportunities to discuss and reflect upon these issues in research, and we have welcomed the opportunity to do so here.

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