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## **Learning Disability Practice**

### **“I just felt there was a little something to say”: an exploration of what motives individuals to participate in an oral history project**

#### **Abstract**

Time is running out to preserve the history of long stay institutions for people with learning disabilities. Researchers must work quickly if they are to gather the personal stories of those who lived and worked in these establishments. Having knowledge and understanding of what motivates people to participate in oral history projects can help researchers to recruit and retain those whose stories are a vital link between the past and the future. This article explores key motivations within the context of an oral history project that sought to preserve people's memories of one long stay institution in East Yorkshire.

#### **Introduction**

We all have personal stories to tell; they define who we are and what experiences have shaped us as individuals. Being able to tell these stories and be heard is an empowering experience (Malacrada, 2006). They provide an opportunity for self-reflection, allowing us to understand and learn from past events that in turn may guide our future actions. In some cases it may lead to a redefinition of ourselves in light of what we discover, allowing others to do the same. For some people telling their own story can facilitate a change in self-identity moving from victim to survivor or from the oppressed to the resister (O'Driscoll and Walmsley, 2010). Up until the 1990s the personal stories of those who lived and worked in long stay hospitals for people with learning disabilities were largely unheard. They represented a hidden part of social and medical history. As Ryan and Thomas (1981) once observed the history of people with learning disabilities is generally represented by those working for or against them. Moreover, the history of the staff working with them has also been a largely unacknowledged story, a possible consequence of the parallel stigma that both groups have historically experienced (Mitchell, 1998). The publication of the books *'A Fit Person to be Removed'* (Potts and Fido, 1991) and *'Forgotten lives: Exploring the History of Learning Disability'* (Atkinson et al, 1991) was to act as impetus for

change as they were to show that people with learning disabilities could be actively involved in both researching and recording their own life story but that such stories could provide valuable lessons for the future. Since then a number of oral history projects focusing on long stay hospitals for people with learning disabilities have been undertaken across the UK. The most recent 'Hidden, Now Heard' is one of the largest projects and seeks to record the personal histories of patients, family members and staff of 6 long stay hospitals in Wales (Learning Disability Today, 2015). Yet such projects only scratch the surface. There are many hospitals whose history remains hidden from view and time is running out to preserve people's memories of them. There is therefore a real urgency to gather these stories before it is too late. Understanding why people choose or conversely choose not to participate in oral history projects and the processes that maybe employed to support them in their role as storytellers is essential to their success. The following article explores these issues within the context of an oral history project undertaken by Purple Patch Arts and the University of Leeds to preserve the memories of people who lived and worked at Brandesburton Hall, a long stay hospital for people with learning disabilities in East Yorkshire.

### **Background to the project**

Originally the country home of Colonel James Harrison, Brandesburton Hall was opened as a 'mental defective institution' in 1932, with an eventual capacity for 365 residents. It became home to an increasing number of residents, with the 1970s seeing it almost full. As times and attitudes changed towards the living situations of those with learning disabilities, there was a move towards smaller community units, and residents were discharged and the hospital run-down, finally closing in 1995. Brandesburton Hall had been the only home many of its residents had known and inevitably the transition from large institution to small unit proved difficult for many. The life they led, and their experiences at Brandesburton Hall were in danger of being lost as residents aged and died, so it was with this in mind that the project idea was born and funding sought.

There were four main project aims:

- Find out about institutions for people with learning disabilities in the East Yorkshire area.
- Make the stories about the institutions available to a wider audience of people.
- Preserve the history in a way that will be accessible for generations to come.
- Improve societal attitudes towards people with learning disabilities and their families thus tackling the issues of discrimination and social exclusion.

## **Method**

The project team were interested in gathering the personal stories of four key groups. This included previous residents of the hospital and any family members; those who had worked at the hospital in a paid capacity and members of the local community in which the hospital was situated. Participants from each of these groups were recruited via an advert in a local newspaper, posts in community Facebook sites and word of mouth. Ethical approval was sought from the School of Healthcare Research Ethics Committee. Individuals were provided with an information sheet that outlined the aims and objectives of the study. This was also made available in an accessible format. Participants were invited to discuss their memories in a semi-structured interview or a focus group. Interviews were recorded and then summarised. Anonymity was assured unless otherwise agreed. As part of the interview respondents were asked why they felt it was important to tell their story and what they hoped others might learn from it. The responses to these questions have been organised under three key themes: 'being heard', 'preservation' and 'education'.

## Findings

### *Theme 1: Being Heard*

Many participants felt that they wanted to 'tell their side of the story'. This notion of 'story telling' was felt by many participants to be an important rationale to taking part in the study:

*I'm a great believer in that stories should be told...I just think everything is about stories really, I just think it's an important part of history that needs to be told and not to be forgotten about...I think it has great power the telling of stories, and it can heal, like I said I think there was a lot of good things about Brandesburton but there was a lot of sadness and distress and I think being able to tell your story and to feel that you've been heard I think is really important for people telling the stories (Participant 13)*

This notion of storytelling was also linked to the idea of participants 'putting something down' or 'on the record':

*'I would like something to go down, you know, on the hard drive or whatever, just for posterity really as much as anything, to tell my side of the story'. (Participant 1)*

For others the interviews provided an opportunity to justify certain historical actions and in doing so reflect upon them

*"For people who have always had these misconceptions or other ideas, I want them to be able to know...that I am not sorry for what I did and I would do it again...I had no choice to do what I did and I hope people do finally understand that, if I hadn't who knows what would have happened after that..." (Participant 14)*

*"...as for working there that we gave the best care we could with the resources that were available to you at the time" (Participant 8)*

This quote highlights another reason for participants taking part in the project. For some, they felt that the interviews provided them with an opportunity to tell their own stories of living and working at Brandesburton. It could be suggested that for many participants, being able to tell their own stories gave them 'a voice' and a chance to be heard before it was too late

*"I just thought, well, you know, it's nice to get it out and other people know about it, you know what I mean, or it's gonna die with me isn't it?"* (Participant 11)

For other participants, they did not feel that their story had any significance and were not sure what people could learn from their stories. For these participants, their reason for taking part in the project was influenced by family and friends who felt that what participants had to say was important and offered them the opportunity to learn more about their own family history.

*"I didn't think it was [important to tell my story] but our Sandra pushed me in to it...I said I wasn't doing it, I said no, I'm not and she rung up or something...our Sandra did that...she got me in to it...I didn't think it was [important] I thought surely there's somebody else..."* (Participant 4)

Conversely many others declined to participate. For some, particularly family members of those who had lived at the hospital, it represented a chapter of their lives that they did not wish to revisit as the memories of having to give their child up to be cared for by others was far too distressing. For others their decision to decline was borne out of a concern for maintaining people's privacy.

### *Theme 2: Preservation*

Linked closely to the notion of 'story telling' was the idea of 'preservation', particularly around remembering the history of the hospital and the people who lived and worked there. Several participants talked about the importance of preserving the history of the hospital, not only for future generations but also in remembrance of those who lived and worked there:

*"I understood it's a piece of history that is going to be lost and I think if it is completely going to be lost and these units are never re-established then it is worth preserving what Brandesburton Hospital and what many of the other hospitals were about...its surprising that it isn't really, I thought the history would have been recorded somewhere but apparently not..."* (Participant 9)

Another participant noted:

*"in some respects I think I wanted, I suppose share both sides of the process, both sides of the coin in terms of it wasn't all good and it wasn't all bad... i think it is important for the people who lived there all their lives that people remember, I suppose remember them and remember Brandes... because it was big part of their life and whether it was good, bad or indifferent it was still their home for a long time....".* (Participant 21)

For some participants, the passing of time was a key reason for taking part in the research project and sharing their experiences of living and working at Brandesburton:

*'...it was a small part of the hospital [the dental service] and I just felt...it's history, if you don't get us now, 20 years from now we'll be croaking it and I just feel that there was a little something to say, that those people at Brandesburton had a dental service, it was provided'.* (Participant 3)

### *Theme 3: Education*

Some participants felt that people in the future could learn from their stories. In this project, two of our aims were centred on learning more about institutions for people with learning disabilities, as well as hoping to improve societal attitudes towards people with a learning disability. However some participants stressed the importance of discussing their stories within the context of the role of institutions in England and the types of caring practices that were used at that time. As one participant reflected:

*"I think people have got to realise that these places did exist for the good or for the bad... if there's improvements to be made looking after people with learning disabilities in the future then they can learn from the old situations...they can actually gain knowledge and take the good things as well as the bad things and work on those to improve, they've got a guideline haven't they to either improve or whatever, that's what I think anyway"* (Participant 17)

The interviews gave staff an opportunity to reflect on current practice and how it had changed over the decades:

*"Because I am getting old now and I think you forget sometimes all those changes that have occurred over the course of your lifetime so for me now, people with a learning disability are living in community settings, they're integrated, supported to live independently and sometimes I've got to remind myself that when I first started, that's not how it was"* (Participant 19)

In other people's statements there were explicit warnings for the future

*"They'll learn that institutions were bad places or potentially very bad places and that it easy to get sucked into them and very difficult to break away from as well...but I hope if people recognise that, there is less likelihood of it happening"* (Participant 5)

As well as learning about good and bad care practices from the different time periods of the hospital, some participants hoped that the stories would help to challenge existing attitudes of people with learning disabilities.

*'I hope people will learn one thing, that although they have a handicap they are still human beings at the end of the day and they have a right to all the things that we have a right to...I mean people were frightened of them because they didn't understand...I would have liked to have seminars for outside people so they could ask questions and then could have felt that they were more part of it and that they understood it much better'.* (Participant 2)



## **Discussion**

People choose to participate in oral history projects for very different reasons. The findings from this project revealed that many felt that they had a story to tell and wanted others to have an opportunity to hear it. For some people with learning disabilities, the right to tell their story might be denied to them by those who make the assumption that it could cause them distress; a stance that can essentially deny individuals their basic right to speak and be heard (Rolph, 1998). For staff and families there may have been a lack of opportunity to tell their story (Atkinson and Walmsley, 2010). To address these issues people need to be given an informed choice. In the first instance they need to be aware of the existence of projects such as this and how to access the research team. Sending posters and leaflets directly to local learning disability services can be a useful strategy however from our experience information may not always be shared with the people who need to know. Whilst Facebook has been shown to be effective in reaching hidden groups (King et al, 2014) issues such as the age of potential respondents and differences in technological ability may affect their interaction with this medium. Employing a mix of traditional (e.g. newspaper advertisements) and contemporary social media is therefore likely to be more effective. Participants also need to be made aware of the potential benefits and risks involved in telling their story (Greaney et al, 2012). Likewise they need to be clear how their stories may be used and by whom and this includes in the future. The availability of clear and accessible information is therefore vital as is allowing participants to have control over what aspects of their story, if any, they wish to tell. This can also be encouraged through the deployment of semi structured as opposed to structured interviewing approach (Bryman, 2015). Unfortunately distress is sometimes an unavoidable consequence of story telling so the provision of effective support through the display of compassion and empathy is important (Dickson-Swift et al, 2007). The availability of a trained counsellor can also add an extra layer of support should the distress prove to be enduring (Ellem et al, 2008).

As we enter a time where financial cuts to individual benefits could herald a return to institutional type services (Grieg, 2016) having an opportunity to hear stories about people's experiences of the past are important for informing future directions (Atkinson and Walmsley, 2010). Much can be learnt from those with first hand experience of long stay hospitals and these can act as an important counter balance to official histories often written by those without the benefit of direct experience. Long stay institutions are traditionally viewed in official accounts through a negative lens however the results of this project appear to support the conclusions drawn by Rolph and Walmsley (2015) that people understand and experience the same situation in different ways and that for some there was a feeling that people did their best. Oral history projects should give people the opportunity to provide an alternative perspective on a generally accepted history and to defend or justify their own involvement. This needs to happen without the fear of recrimination so the skill of the interviewer is in creating a safe and supportive environment that includes being interested but non-judgmental (Gysels et al, 2008). Assurances around confidentiality and anonymity may also engender trust between the participant and researcher thereby encouraging engagement (Burns and Grove, 2009). Moreover, for those who decline to participate there must be respect for their decision regardless of any potential consequences such as part of the story being lost.

The chance to have one's story heard by others clearly acts as an important motivator for engagement in an oral history project, therefore researchers need to make clear to potential participants the range of mediums for dissemination that will be harnessed for this purpose. Dissemination can take on various forms but demands that the researchers have a clear understanding of the requirements of the target audience (s) (Cribb and Hartomo, 2002). A study that fails to outline how someone's story will be employed can result in disinterest from potential participants, resulting in a smaller number of persons taking part. Furthermore, in recent years there has been an increasing emphasis from the government and research funding councils on the need for academic researchers to evidence the economic and social impact of research. Therefore, having a clear strategy for using and disseminating oral history research can not only optimise

the chance of key findings reaching the target audience (s) but, it can also create opportunities for genuine dialogue, learning and shared understanding on a range of oral history topic areas.

## **Conclusion**

It is imperative that people work quickly to preserve the history of long stay institutions for people with learning disabilities. This article has shown that a range of motivations exists for why people choose or conversely choose not to participate in oral history projects. Having knowledge and understanding of these factors can help potential researchers to recruit and retain those whose stories are vital link between the past and the future.

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