ORIGINAl ARTICLE

‘My memory’s back!’ Inclusive learning disability research using ethics, oral history and digital storytelling

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Accessible summary
• This article is about how people with learning disabilities helped to produce a history about Australia’s oldest and largest purpose-built institution for people with learning disabilities, Kew Cottages.
• The study uses oral history to empower people with learning disabilities to tell their stories in their own words.
• I believe that it is important for oral histories to be accessible for people with learning disabilities. So I used a new form of history-making, digital storytelling/histories, to produce a DVD using text, sounds and images.
• This research is important for people with learning disabilities because it explains how traditional oral history techniques can be used with new media technology to create collaborative, meaningful and accessible publications.

Summary
The following article outlines the methodological approach used to include people with learning disabilities as active participants in an oral history produced in Australia. The history sought to document life inside Kew Cottages, Australia’s oldest and largest specialised institution for people with learning disabilities. This work furthers existing research being conducted with people with learning disabilities in the fields of oral history and life history. The article explores: research ethics, the value of oral history and the positive benefits for inclusive learning disability research using digital storytelling/histories.

Keywords Collaboration, digital media, ethics, history, learning (intellectual) disabilities

Introduction
Can academic research be inclusive and reciprocal for both researchers and people with learning disabilities? This article argues that it can if research design meets multiple methodology and accessibility needs. In history, inclusive research has primarily focussed upon oral history. The benefits of this approach in acquiring new knowledge have been advocated by renowned academics Alessandro Portelli (1991) and Paul Thompson (1988). Louise Douglas et al. (1988) argued that oral history has uncovered forgotten or hidden voices, using the recorded interview as a major vehicle for recovering the experiences and opinions of many individuals and marginalised groups. Oral histories conducted in the United Kingdom and North America with people with learning disabilities supported this viewpoint (e.g. Atkinson 2004; Atkinson et al. 2000, 2005; Groce 1992; Mitchell et al. 2006; Walmsley & Johnson 2003). Although oral history is inherently inclusive, as it enables people to tell their stories in the first person narrative, its use has often
been confined to the incorporation of ‘marginalised voices’ into text-based resources, whether standard or Easy English, such as books, articles and reports. These resources tend to be produced for an audience with high levels of literacy and vision, excluding all others.

Critics of oral history have purported that this form of history-making is inherently flawed due to the malleable nature of memory and remembrance (Grele 1998). As noted in the seminal collection, The oral history reader (Perks & Thomson 1998, 2006), such claims have long been rejected as most oral historians consider testimony in the same manner as other forms of evidence; it is legitimated and used in association with a range of evidentiary sources. Many contributors to this book noted that oral history represented a significant advancement in research because it enabled rich and complex analyses of national, international and transnational issues through merging personal testimony and archival documentary evidence (Perks & Thomson 1998, Perks and Thomson, 2006). This methodology was adopted and further developed in the oral history of Kew Cottages.

In 2005, I was one of eight university researchers employed to document the history of an Australian institution for people with learning disabilities, Kew Cottages. When Kew opened in 1887, it was regarded as a world leading facility as it offered both residential care and educational opportunities. Although intended for children, from the outset the institution also housed adults. Initially, 57 people resided at the Cottages; by 1968 this figure peaked at 948 (Manning 2008). In 2001, the Cottages site was earmarked for residential redevelopment and closed in July 2008.

The history project was established in response to the institution’s planned closure. The Victorian Government, which was responsible for the management of Kew, wanted an independent research team to examine the significance of the facility in Australia’s social and cultural landscape. My key responsibilities were to complete an oral history and write an ‘innovative’ book. ‘Innovation’ was defined by the inclusion of residents’ voices in the grand narrative of the institution’s history, but did not extend to making the history accessible for resident interviewees or many other interviewees who had limited literacy skills and/or vision impairment. Unhappy with the exclusionary nature of the proposed oral history, I sought additional funding and devised a publication which met the needs of all participants.

The Kew Cottages oral history recorded approximately 100 h of interviews, from over 80 participants, during a 2-year period. Interviewees included residents, staff, families, volunteers and others associated with the institution. Within this cohort, 16 residents told their stories of life at Kew covering the period 1925–2008. Participants were sought through various avenues including advertising, media reports, word-of-mouth and direct recruitment via letters of invitation. The oral history interviews formed the basis of Bye-Bye Charlie: stories from the vanishing world of Kew Cottages (Manning 2008), which included an illustrated book and a DVD collection of digital histories. This article examines three key areas of inclusive learning disability research which resulted in the production of Bye-Bye Charlie: research ethics, oral history and digital storytelling/histories. The last section, on digital storytelling/histories, represents groundbreaking research which encourages active collaboration between researchers and participants using new media technology. My project extends the work of notable researchers in oral history, life history and learning disability such as Dorothy Atkinson et al. (1997, 2000), Atkinson (2004) and Atkinson et al. (2005), Duncan Mitchell et al. (2006), Sheena Rolph (Atkinson et al. 2000; Atkinson et al. 2005; Brigham et al. 2000) and Jan Walmsley (Atkinson et al. 1997; Atkinson et al. 2000; Walmsley & Johnson 2003). But, more importantly, it fills a void in oral history and learning disability methodology by enabling the production of outcomes which are appropriate for people with learning disabilities while appealing to a general audience. This advancement has resulted in Kew’s history moving beyond the narrowly defined field of learning disability and into a wider cultural context.

Research ethics – consent and assent

In the past, oral history participants have often been recruited by researchers as a means of eliciting new information or perspectives on historical understandings. Their participatory rights as active collaborators have tended to be pushed aside in favour of researchers’ needs to publish outcomes in a swift and efficient manner. While interviewees may have been given a transcript to edit or segments of their testimony to read in situ, generally their contribution to historical construction ended at the close of the interview. The Kew project pushed the boundaries of standard oral history methodology by actively encouraging interviewees to participate in the areas of ethics, research data generation and production.

In Australia, academics conducting research with ‘human subjects’ are required to follow research guidelines governed by university ethics committees. Obtaining informed consent from participants is considered paramount. But how do researchers gain such consent when a person’s cognitive abilities preclude them from legally making such decisions? This question was at the centre of devising a research ethics model for the Kew project. It was necessary to establish a consent process that was meaningful and empowering for all participants. As the majority of Kew residents had little or no literacy skills, a dual consent process was designed to afford this group of interviewees the same rights and privileges as other participants. This system used concepts of informed consent and assent.
The informed consent process was typical of most humanities and social science projects. Once a person volunteered to be interviewed, they were informed about the project’s main research aims and outcomes. The interview structure was explained and copies of the Information Statement, detailing the project and Consent Form were mailed out. At the first recording session, the Information Statement and Consent Form were reviewed with the interviewee to ensure that s/he understood the project and her/his role. Two Consent Forms were completed, one for the interviewee’s personal records; another for the research team. Finally recording commenced.

Of the 16 residents interviewed for the oral history, the consent process was used on four occasions. The decision to apply this approach was based upon preliminary discussions with potential interviewees as well as consultation with a close relative, friend or advocate. Seeking advice from a third party who knew the potential interviewee was meant to ensure that consent was genuine and given freely. The involvement of a third party was not standard for all interviewees. Although this was a double standard, it was one that emerged through a sense of justice rather than exploitation. Soon after fieldwork commenced, it was obvious that the assistance of a third party was unnecessary. This process actually served to undermine the advocacy rights of people with learning disabilities who were more than capable of making informed decisions. I would remove this discriminatory regulation from future ethics regimes.

The second model for research participation illustrated the challenges faced by researchers working in the field of oral history and learning disability. This model concerned people with learning disabilities who were unable to give informed consent. It utilised two forms of permission – consent and assent. The research team was reliant upon the advice of Kew Cottages staff or a person close to a resident as to whether s/he fell within this category. If a person with learning disabilities was deemed unable to give informed consent then this was obtained from a person closest to the individual. In most instances this was a family member, however, in cases where no family contact was maintained a guardian or advocate signed on a resident’s behalf.

An important aspect of the consent/assent process was the requirement that a third party representative be present at all meetings and interview sessions. The rationale behind the regulation was to make the interview session more comfortable for the interviewee and to ensure his/her wellbeing. As some of the issues to be explored involved violence, neglect and abuse, the physical and psychological wellbeing of an interviewee was of concern. Acknowledging this risk, counselling was made available to all interviewees. Third parties were chosen by people giving consent and tended to be staff who worked at Kew or in community houses where former residents lived, known as Community Residential Units (CRU). This aspect of the consent process proved to be problematic.

The second stage of the consent-assent model was seeking assent from each resident. The assent process gave the resident freedom to determine whether s/he wished to be part of the project, while obtaining consent from a guardian, family member or advocate met the demands of human research ethics guidelines. The assent stage commenced with a meeting of all parties who were to be involved in a resident’s interviews and meetings. At this gathering, the resident was informed about the project and his/her role. An Easy English Information Statement and Assent Form were used to assist in this process. If the resident agreed to participate two copies of the Assent Form were completed, one was kept by the resident, the other by the research team. If possible, the resident signed the form, whether through letters or a mark, if not, the third party signed on his/her behalf. If a resident did not wish to participate no further action was taken. Fortunately, all of the residents who were approached to be involved in the project assented. I would recommend the assent process to researchers as it empowers people with learning disabilities while adhering to ethics guidelines concerning voluntary participation.

Although the assent model was inclusive there was a fundamental flaw in the ethics design which resulted in the disempowerment of one resident. This problem was associated with the use of pseudonyms. My oral history approach differed markedly from the majority of published research regarding learning disability and mental health as I did not automatically de-identify subjects. Instead, interviewees were given the choice of using a pseudonym for part or all of their contribution. There is no question that pseudonyms are essential when relaying information about people in State care who cannot give informed consent/assent. My decision not to arbitrarily de-identify people was made in an effort to empower participants in claiming ownership of their history and to demystify the often ‘clandestine’ nature of life inside State institutions. People who lived at Kew were individuals with different needs and desires. They did not identity themselves or refer to one another as ‘John B’ and ‘Mary K’. Patrick Reed (2006) gave powerful testimony about violence at the Cottages, while Wendy Pennycuick (2007) spoke about her enjoyment of making beaded purses in the Workshop. Resident interviewees were often proud of their achievements and wanted others to know and understand their personal histories.

The issue of de-identification was raised in both the consent and assent forms. If a person giving consent agreed to a resident’s name being used, but the resident preferred to use a pseudonym then the resident’s wishes were met. Out of the 16 residents who participated in the project two were allocated pseudonyms. This option was chosen by Clare Turner who gave informed consent. Clare wanted to
openly talk about her mistreatment at the Cottages but did not want her family to learn of her suffering (Turner 2005). In regards to the second resident, the relative giving consent requested that a pseudonym be used. When the resident was given the option of a pseudonym in the assent process, he chose to use his real name. At this time, the resident was living at the Cottages. I raised the conflict with the resident’s legal guardian, the Manager of the institution, noting that interview materials would not be used in a derogatory or negative manner. I was instructed to uphold the wishes of the family member giving consent and to use a pseudonym.

I was opposed to the decision to override the resident’s request to use his real name for two primary reasons. As Erving Goffman (1961) noted in his study of asylums, institutions were notorious for stripping people of their identity. I believe that imposing a pseudonym against the resident’s wishes reinforced this ideal and flouted his advocacy rights. In addition, this decision resulted in the resident being excluded from one of the most innovative aspects of this project—the production of residents’ life histories to foreground their experience and emphasise the centrality of their role in the institution’s history. Life histories were not constructed for those resident interviewees who were allocated a pseudonym as such details could have revealed their identities. The resident in question was disappointed at being excluded. To prevent this dilemma in subsequent projects, I would locate the issue of de-identification solely within the assent process.

Another problem associated with the consent/assent approach was the obligatory attendance of a third party in interviews. At times the involvement of a third party known to the resident was invaluable as they were able to explain the project or phrase questions in a manner understood by the resident. They also prompted stories. However, sometimes interviewees were hesitant to discuss issues in their presence. For example, it was not unusual for an interviewee to shoot a sideward glance for approval before relaying accounts of sexual encounters or staff mistreatment. This was significant when the third party was a staff member. This reticence was not necessarily a reflection upon the character of the staff member present, although this may have been the case, but rather an awareness of possible repercussions for breaking the code of silence that existed in the institution. The residents did not want to appear to be ‘making trouble’ or criticising those charged with their care.

A couple of third party representatives also interfered with the interview process by diverting discussion away from contentious topics and/or leading an interviewee. For example, one-third party representative interjected with the question ‘What were the good things about the staff? Tell us who the good staff were’, when I was questioning a resident about staff violence at Kew (Manning 2006). The interviewee appeared to be uneasy after this interruption so the interview shifted in focus. I approached this issue once again through a different line of questioning, by situating violence in a broader context of resident against resident, resident against staff and finally staff against resident. This questioning not only allowed the interviewee to contribute vital evidence, but revealed to the third party that this was not an exercise in demonising staff. The history considered violence in a multiplicity of forms where victims and aggressors emanated from residents, staff and others within and outside the institution. At times, it was critical to make the third party just as comfortable with the interview process and environment as the interviewee.

Perhaps Jan Walmsley’s (1998, p. 132) approach to third party involvement would have been more suitable, to offer this as a flexible option exercised through consultation with participants with learning disabilities. This approach places the power of inclusion and control directly in the hands of the interviewees. Despite these problems, the philosophy behind the consent/assent model was sound. With modifications, it could be an effective research ethics model for researchers and participants across a range of disciplines.

The value of oral history

Oral history has become an important collaborative research method used by many academics when working with people with learning disabilities. Noteworthy accounts of inclusive learning disability research using oral history have included: Forgotten lives (Atkinson et al. 1997), Good times, bad times (Atkinson et al. 2000), Witnesses to change (Atkinson et al. 2005) and Exploring experiences of advocacy by people with learning disabilities (Mitchell et al. 2006). This form of research has enabled people with limited literacy skills to contribute knowledge about their experience of living with learning disabilities in different social, political and cultural contexts. The type of qualitative data garnered through various oral history techniques, for example interviews and focus groups, has provided information previously unavailable in archives such as patient files, government documents and media reports. In regards to Kew Cottages, oral testimony was essential in recording the ‘unofficial’ history of the institution. As ‘outsiders’ we may never have a ‘true’ picture of this often secret world, but personal testimony has enabled a more humane account of institutional living—one which extended beyond the spatial geography, policy and medical history which dominates most historical accounts of similar institutions.

My experiences working on the Kew oral history highlighted the importance of this research method when working with people with learning disabilities. Participants with learning disabilities were confident in exercising control mechanisms afforded to them. The Kew study further revealed that not only can participants be fruitful in providing information; they can also contribute to the
creation of innovative outcomes which cater for academic and non-academic audiences.

In all oral history projects it is essential that participants understand their rights to determine the nature of their involvement. In regards to the Kew project, before each recording, I ran through a series of controls available to all interviewees to shape their contribution. Two critical mechanisms included choosing not to answer questions and stopping the interview at any time. My experiences correlated with previous studies (Atkinson 2004), that people with learning disabilities were forthright in utilising these functions. For example, on my first interview session with John Goddard, he declared, ‘I’ve had enough now, come back another time’ (Manning & Goddard 2006). Another resident bluntly told me, ‘I don’t want to answer that question’ (Manning & Evans 2006), when asked about why he was expelled from his Day Program. The willingness of residents to exercise power in both the meetings and interview sessions reflected the active and reciprocal nature of the interview relationship. This dynamic was evident in my dealings with resident, Ralph Dawson.

The following scene was created using my field notes dated 31 July 2006. I was preparing to leave a CRU that housed five men who were relocated away from Kew Cottages. As I picked up my bag I turned to Ralph and said:

CM: So Ralph, is it still okay if I come and talk to you on Thursday night about what it was like to live at Kew?

RD: Kew? My memory’s gone, I don’t remember nothing about Kew.

CM: Your memory’s gone? But you’ve told me so many things about Kew over the past few weeks.

RD: Yeah. My memory’s gone. It went out the front door, got into a rocket and went off to the moon. I don’t have no memories of Kew no more.

CM: Oh that’s a shame I was really looking forward to our interview. Maybe I day it will come back.

RD: Yeah. Maybe.

I shook Ralph’s hand and walked over to Donald Starick to say goodbye. Pointing to his jumper, Donald informed me, ‘I got this with my money’. Ralph yelled out, ‘What money Donald?’ ‘For the interview’. Ralph leapt out of his chair and rushed towards us. ‘You got paid? How much did you get paid?’ I answered ‘$50’. ‘$50! My memory’s back!’ Ralph was even more excited when I told him that he would get CD copies of his interviews as well as a copy of the history when it was published.

This story was just one example of the many comedic episodes I witnessed when interviewing people. However, this exchange represented more than a ‘funny anecdote’. It reflected the ways in which people with learning disabilities exerted power both within the research project and the institutional world in which they lived. Although efforts were made from the 1980s to increase self-advocacy for people with learning disabilities, many Kew residents were unable to fully enjoy such rights as large-scale congregate care often subsumed individuality and personal empowerment. This exchange was indicative of the way in which many residents of long-term State care facilities wielded control over their daily lives. The creation of histories describing these power relations have the potential to be valuable tools for support staff who work with former residents in CRUs. They foster a greater understanding of residents who have made the transition from large-scale congregate care to more intimate accommodations.

While living at Kew, residents were expected to adhere to institutional rules. For example, Ralph was required to prove himself ‘worthy’ and sign a ‘good behaviour’ contract before being allocated a higher standard of accommodation at Kew than the dormitory in which he lived: ‘I signed a contract...[to] be good and not punch someone and swearing at someone (2006)’. Ralph was taught to use non-confrontational methods of negotiating power in his everyday life. He was using this mechanism to assert his power in regards to his involvement in the Kew project. Ralph felt triumphant after our exchange, bragging to his sister about how he had fooled me with his ‘memory loss’ and was successful in securing $50. According to Ralph, I had been well and truly hoodwinked!

The provision of tangible forms of payment for interviewees highlighted the reciprocal nature of the oral history. However, Ralph was not purely concerned with monetary reward. His inclusion resulted from an interest shown in the project after watching his housemates record their stories. When I visited his unit at Kew Cottages and subsequently his CRU, Ralph always spoke about life at Kew. Ralph asked if he could be involved well before he knew about any interview payment. His willingness to contribute to the history came about through a genuine desire to tell his story.

I believe that Ralph’s ‘memory loss’ was due to his frustration at the length of time that it took for him to be interviewed. As he was unable to give informed consent, I had to wait until his sister returned the consent form before working with Ralph. This took nearly 2 months. On my weekly visits to Ralph’s CRU he always asked when it was going to be ‘his turn’. My response was that I had to wait until I had heard from his sister. As the weeks passed, Ralph’s enthusiasm waned. I was fortunate that the provision of an interview payment reinvigorated his interest. Ralph’s actions revealed that the delays associated with the consent/assent approach could serve as a deterrent for some people who wished to be involved in such projects. This problem appears to be unavoidable as consent must be obtained from someone who is considered to be legally responsible.
A vital research method for the Kew project was the use of case studies to record daily life at the institution. As Anthony Lovell (2006) noted in his study of self injury, case studies serve as a filter to analyse particular issues. They also bring to life an institutional world through first hand narratives. Ralph vividly described the division of his dormitory between the ‘small boys’ and ‘big boys’, the unbearable noise that drove him ‘up the wall’ (Dawson 2006), working as an artist and his desire to escape institutional life. Like many other residents, Ralph yearned to leave the Cottages. But once he moved away, he struggled with the loss of some of his independence and freedom. Despite strict regimentation at Kew, Ralph used his leisure time to visit friends and explore his local neighbourhood. It was not unusual to see him strolling to the nearby shops or around the Kew grounds. When he moved into a CRU such freedom was virtually non-existent. Although CRU staff were active in familiarising Ralph and his housemates with their new surrounds, when at home they often remained within the confines of the property. They ventured out to work, programs and assorted organised activities, but generally with staff support.

When I first met Ralph he forthrightly declared ‘I can’t wait to leave Kew, I hate Kew (2006)’. This viewpoint altered shortly after he was relocated into a CRU and he spoke about the sadness of Kew’s demise. Ralph missed Kew, not the living conditions, but his friends and independence. Ralph’s story provided insight into the impact of institutional living and deinstitutionalisation on an individual’s life. Without oral history, analysis of the relocation process would have been reliant upon quantitative data gathered by government and academic agencies with little or no first hand qualitative evidence from those most affected by these programs – the residents. In the Kew project, oral history enabled a more complex and personal understanding of the impact of government policy on the lives of people with learning disabilities. It also gave interviewees an opportunity to share memories and express opinions that were lacking in archival sources. Oral history provides a vehicle through which people with learning disabilities can contribute to historical accounts of their lives in a manner rarely met by traditional document based publications.

The oral histories of Kew residents, such as Ralph, provided rare glimpses into the complexities of long-term care at State facilities. Testimony revealed: the spectrum of emotions experienced by residents, their attachment to geography and place, the evolution of identities in an institutional context and the unique power relations that existed in a facility designed to house both children and adults. Although Kew Cottages was in many ways ‘typical’ of many other institutions, it was unique in its demographic makeup and longevity in the face of deinstitutionalisation policies of the late 20th century.

**A new form of collaborative research – digital histories**

Soon after I commenced working on the Kew project, I realised that the task for which I was employed, to write a book, was problematic for many interviewees. Limited literacy skills were a constant problem for most residents and some staff at the Cottages. My book was to be a 70 000 word manuscript with a small selection of images. Over 85% of residents who participated in the project were unable to read fluent text or fully engage with Easy English resources. Although many of these people could have appreciated the published photographs, one resident was also vision impaired meaning that her access to the history was reliant upon someone reading the text and describing the images. Despite the project being innovative, by including the voices of people with learning disabilities, unfortunately the production of a book failed to provide a meaningful, accessible history for many participants. In order to rectify this situation, I sought alternate publishing formats and discovered a form of history-making called digital storytelling. This approach ensured that inclusivity went beyond the bounds of research methodology and makes this study a model for future researchers who wish to engage with people throughout the academic and general communities.

Digital storytelling evolved with the emergence of new digital media which enabled people with limited technological knowledge to create short 2–5 min stories about an aspect of their lives. These stories were first person narratives in which authors wrote a script and selected a range of audio, image and video files to produce a ‘mini-movie’ (Lambert 2002). I decided to utilise the philosophy of digital storytelling and apply it to the Kew project through the creation of digital histories. These histories were stored on a DVD that accompanied the book – it was one publication.

The use of a DVD, rather than a CD, was due to the fact that most residents had access to a television and DVD player, and the requisite skills to use this technology. In addition, a DVD offered more storage space which was critical given that 25 digital histories, a timeline, maps and project information were to be included. The production of the DVD contributed to the reciprocal nature of the history as it catered to the specific needs of people who could not fully engage with a standard history book.

The rationale behind the production of the DVD was to create an accessible resource which mirrored the book manuscript. However, the specific requirements of digital media production resulted in some differences in the physical layout. In the book, the central chapter, chapter six, is comprised of a collection of short life histories written in collaboration with participating residents. The placement of these life histories was intended to reflect the central role that residents played in the history. When creating the DVD,
I was concerned that this centrality was subsumed within the physical layout of the menu structure. Therefore, in order to foreground this feature on the DVD, the life histories were given a separate menu button. The button was placed underneath one which read ‘General History’, a section which contained the digital histories of the remaining 10 book chapters. In the book, the life history collection was entitled ‘At the heart of Kew’s history’, on the DVD it was labelled ‘Residents’ Stories’. The different titles adhered to the protocols of using short, descriptive labels for electronic media resources and was intended to direct users to key areas of interest. Despite the DVD layout being different, the focus of the history remained intact – to privilege the stories and experiences of residents who lived at the Cottages.

The production process regarding the digital histories differed between the sections ‘General History’ and ‘Residents’ Stories’. In the ‘General History’ section, the digital histories were thematic in content and were comprised of a main narrative and segments of interviews sourced from a range of project participants. Content did not highlight a single person’s account, but reflected multiple perspectives. Therefore, I was the chief narrator of the story and chose the accompanying audio and image sources. There was one divergence in this process. In the story about violence, abuse and neglect at Kew, I worked with three residents whose testimony and images were included. Given the sensitive nature of the material being used, it was important that such consultation took place.

Collaboration was paramount in the creation of the digital histories contained under the section ‘Residents’ Stories’. In the spirit of digital storytelling, I worked closely with residents as a facilitator, enabling them to tell the stories that they considered most significant. On some occasions, the stories chosen by residents were not necessarily the most evocative or well articulated accounts of life inside a State institution. However, digital storytelling involves individuals creating a unique and self-reflective representation of their lives. This process clearly illustrated that sometimes what we choose as ‘professional researchers’ does not necessarily accord with the opinions of our subjects – a valuable lesson for people who strive to recreate the life experience of others. In producing the life histories, I spoke with residents about their preferred stories and assisted them in locating relevant audio and images to illustrate them. In regards to the resident who was vision impaired, I described the photos and gave options about which ones would be most suitable. For all residents, I wrote a script which set a context for the residents’ stories and together we decided on the placement of audio and image files.

After the resident’s story was created using specialised software, the short film was played to the interviewee for his/her comments and approval. Once the resident was happy with the final product it was signed off for inclusion on the DVD. The residents’ participation in the production of digital histories was a rewarding experience for all parties. Many residents called friends, support staff and family to come and view the finished product. As a researcher, it was heartening to witness the positive reception from viewers. All of the residents embraced the film making process and proudly screened their stories whenever possible. Beyond those associated with Kew Cottages, these films have proven to be educative and entertaining. They have successfully been featured in arts festivals, writers’ festivals, public lectures and conferences. The films have also been used as classroom resources in secondary and tertiary institutions across health science, humanities and social science disciplines. The overall response to the digital histories has been extremely positive and reinforces the value of this type of history-making.

Although the inclusion of digital histories was a major advancement in creating accessible history, the overall imagery represented in the DVD was somewhat problematic. As with many photographs taken in mainstream society, images of people at Kew tended to be ‘happy snaps’ of special events and publicity shots taken to expound the positive work being done at the Cottages. There were very few images of the hardship and neglect endured by residents for most of the institution’s history. There were approximately 1000 images displayed on the DVD. Although some of these represented the poor fabric of the facility, the ‘happy’ photographs of residents tended to mask the everyday reality of confinement in substandard living conditions. In order to counterbalance the positivist imagery, audio narration and interview excerpts describing deprivations at Kew were used in juxtaposition to photos. Audio was also used to contextualise the provenance of some photographs. Despite this problem, the digital histories provided a new form of collaborative research which enabled people with learning disabilities greater power in determining not only their oral history contribution, but its representation.

**Conclusion**

Working with people with learning disabilities for the Kew Cottages project was a rewarding experience. It reinforced the basic tenets of good oral history practice – that by providing an environment of trust, understanding and mutual respect positive outcomes will generally result for participants. My research also signified an important advancement in oral history methodology through its multifaceted approaches to inclusiveness and history production. Residents’ testimony was thought provoking, insightful and entertaining. Their involvement in the project highlighted residents’ willingness and ability to exercise certain powers within Kew Cottages, as well as the oral history and digital history paradigms. The book and DVD, *Bye-Bye Charlie*, serve as a new model of collaborative research. This approach truly brings to life the voices and
images of people with learning disabilities, while making their history accessible and engaging to a broad audience.

References


