

**\* This was written as a paper to be read aloud to conference participants, therefore references are strictly limited. Pseudonyms have also been used for some interviewees upon their request, or their consent-givers request.**

### **Working with the ‘Children of the Darkness’**

In 2005, an interdisciplinary team of researchers at La Trobe University in Australia commenced a project to document the history of one of Australia’s most significant institutions for people with learning disability, Kew Cottages. The Cottages are located in a leafy Melbourne suburb, in the state of Victoria. The facility was opened in 1887 and is earmarked for closure in 2008, residents being relocated into community residential units. Although the Cottages were intended to house children with learning disabilities, throughout its history many adults have called it ‘home’. In its heyday, in the 1970s, there were nearly a thousand residents living onsite, now there are close to one hundred. I am one of eight researchers working to document the history of Kew Cottages.

The research team at La Trobe consists of people from history, social work, gender, sexuality and diversity studies and media studies. Our project outcomes include two books, one based on archival research, the other an oral history, as well as scholarly articles, an exhibition, website, photo archive and a radio documentary. I am the oral historian for the project. My primary responsibilities are to: arrange, record, oversee transcription, edit and secure consent for 70-90 interviews with those most intimately associated with Kew - the residents, staff, families, volunteers and others, and to use these interviews to create an oral history book and collection of digital stories. I was employed because of my oral history experience, which had mostly been in the field of Indigenous history and human rights. Working in the area of disability was a new challenge – one which I wholeheartedly embraced. This paper outlines the methods that I used to include people with learning disability as active participants in the oral history. It discusses the ways in which residents’ exerted power within the interview situation and examines the challenges of documenting cases of institutional violence and abuse using oral testimony.

In 1956, Dr Reginald Ellery, a former medical officer at Kew Cottages, published a book about his professional career entitled *The Cow Jumped Over the Moon*. He devoted a chapter of his book, ‘Simple Simon’, to his experience of working at Kew. In today’s society, Ellery’s description of the Cottages and its inhabitants is shocking. Yet his attitudes signified a common perception about people with learning disability held by many Australians up until the late twentieth century. He wrote:

Shut away from public sight by a tall hedge, lay a valley of desolation or a slope of shame...It was the Government’s keep for mentally defective children – an eye-sore, a place to shun, an abomination. Officially it was known as the Idiot Asylum; but was referred to by the staff, simply, as “The Cottages”.hovels would have been a more appropriate name. For these unpleasant, louse-tenanted styes ... housed about four hundred of the state’s most degraded mental defectives. Children, mostly, in whose vacant faces there was no lamp of understanding, whose eyes were clouded with a vague perplexity ... Children of the darkness ... This was home to a bevy of poor brainless imbeciles, children born in the mischief of a harmful inheritance and constrained to grow up in mental darkness. It was home-sweet-home to

the idiot who knew not the days, and a bare hearth to the moron who looked wistfully at the sun..<sup>1</sup>

This negative image of people with learning disabilities as passive subjects, unable to effectively speak or advocate for themselves has resulted in their voices being absent in virtually all accounts of life at Kew. One notable exception is the book, *The World of Dolly Stainer*<sup>2</sup>, which includes testimony mostly from a single resident. The oral history component of the Kew Cottages History Project seeks to redress this silence by recording stories and creating digital stories in collaboration with residents.

In recruiting project participants it was necessary to establish a consent process that was meaningful and empowering for all volunteers. As the majority of Kew residents have 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 uses concepts of informed consent and assent.

The informed consent process for the oral history is typical of most humanities and social science research projects. Once a person volunteers to be interviewed, they are contacted by phone and the project's main research aims and intended outcomes are discussed. During this initial conversation, the role of the interviewee and the interview structure are explained. If the volunteer still wishes to be interviewed, a convenient location for the session is chosen and a copy of the information statement and consent form mailed out. At the first recording session, I discuss the various parts of the information statement and consent form with the interviewee to ensure that he/she understands the project and his/her role. I also answer any further questions that arise. Two copies of the consent form are completed, one for the interviewee's personal records, the other for the research team. Finally we commence recording. This approach is standard practice for many academic researchers involved in recording oral testimony as an evidentiary source.

The consent process outlined above was used in relation to three of the Kew residents who were able to advocate for themselves, but had minimal literacy skills. As the information statement and consent form is six pages in length, I worked more closely with these interviewees and consulted with a third party who knew them well to ensure that consent was given freely and was genuine. While the involvement of a third party was not standard practice for all interviewees, I considered it to be prudent in regards to the Kew residents to ensure the protection of their rights. This may appear to be a double standard, but one that exists through a sense of justice rather than exploitation.

The second consent process used in the project relates to people with a learning disability who are unable to give informed consent. This model utilises two forms of permission – consent and assent. If a person with a learning disability is considered by his/her guardian, family member or advocate, as unable to give informed consent then this is obtained from the person closest to the individual. In most cases this has been a family member, however in cases where no family contact has been maintained a guardian or advocate has signed on a resident's behalf. An important aspect of the

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<sup>1</sup> RS Ellery, *The Cow Jumped Over the Moon: Private Papers of a Psychiatrist*, Melbourne, FW Cheshire, 1956, p. 133.

<sup>2</sup> Cliff Judge and Fran van Brummelen, *Kew Cottages: The World of Dolly Stainer*, Melbourne, Spectrum Publications, 2002.

consent/assent process is the requirement that a third party representative be present at all meetings and interview sessions. The rationale behind the attendance of a third party is to make the interview session more comfortable for the interviewee and to ensure his/her wellbeing. Most of the third party representatives are staff who work at Kew or in community houses known as community residential units or CRUs.

The involvement of a third party known to the resident has been invaluable as they have assisted in explaining to residents some of the difficult concepts pertaining to the project. They have also prompted stories and sometimes communicated my questions in a format that was more easily understood by the resident. But at times it has also been a hindrance as interviewees were sometimes hesitant to discuss certain issues in their presence. It was not unusual for an interviewee to shoot a sideward glance for approval from the third party before relaying accounts of staff mistreatment or sexual encounters. This was particularly evident 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 in some instances, but rather an awareness of possible repercussions for breaking the code of silence that exists in most institutions. The resident did not want to appear to be 'making trouble' or criticising those charged with their daily care.

Another problem with a few third party representatives was interference in the interview process by diverting discussion from contentious topics 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. The interviewee appeared to be uneasy after this interruption so I allowed the interview to shift in focus. However 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 technique not only allowed the interviewee to contribute vital evidence, but revealed to the third party that this was not an 'institution-bashing' exercise through demonising staff. The history considered violence in various 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.

Once informed consent was obtained, the second stage involved seeking assent from each resident. The assent process commences with a meeting of all parties who will be involved in a resident's interview meetings. At this gathering, I explain to the resident who I am and what the project is about. I use an Easy English information statement and assent form to assist in this process. If the resident agrees to participate in the project we complete two copies of the assent form. If possible, the resident signs the form, whether through letters or a mark, if not, the third party signs on their behalf, most of the time I record both signatures. The assent process gives the resident freedom of choice to determine whether he/she wishes to be part of the project, while obtaining consent from a guardian, family member or advocate meets the demands of current human research ethics guidelines. At this stage, if a resident states that he/she does not wish to be involved in the project the person giving consent is notified and the resident's participation ceases. If the resident changes his/her mind the process recommences. The assent process has been extremely successful.

In recording oral history it is imperative that interviewees understand their rights to determine the nature of the interview session. Therefore, before the first recording, I run through a list of controls that can be used by all interviewees to shape their contribution. Two of these mechanisms include choosing not to answer questions and stopping the interview at any time. In my experience on the Kew project it has been the interviewees with a learning disability who have been more forthright in regards to these matters. On the first interview session with John Goddard, he declared, 'I've had enough now, come back another time.'<sup>3</sup> Another resident bluntly told me, 'I don't want to answer *that* question', when asked about why he was expelled from his Day Program.<sup>4</sup> The willingness of residents to exercise power in both the meetings and interview sessions reflects the active and reciprocal nature of the interview relationship. This dynamic was evident in my dealings with Ralph.

31 July 2006. 5.45pm. I am preparing to leave a Community Residential Unit that houses five men who have been relocated away from Kew Cottages. As I pick up my bag I turn to Ralph Dawson and say:

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 one day it will come back.

RD: Yeah. Maybe.<sup>5</sup>

I shake Ralph's hand and walk over to Donald Starick to say goodbye. Pointing to his jumper, Donald informs me, 'I got this with my money.' Ralph yells, 'What money Donald?' 'For the interview.' Ralph leaps out of his chair and rushes towards us. 'You got paid? How much did you get paid?' I answered '\$50.' '\$50! My memory's back!'<sup>6</sup>

This story was just one example of the many comedic episodes I have witnessed over the past 15 months when interviewing people for the Kew Cottages Project. However, this exchange is much more than a 'funny anecdote'. It reflects the ways in which people with learning disability exert individual power both within the research project and the institutional world in which they live. Although efforts have been made to increase self-advocacy for people with learning disability, many Kew residents have been unable to fully enjoy such rights as large scale institutions often subsume individuality and personal empowerment.

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<sup>3</sup> Interview between Corinne Manning and John Goddard, 29 May 2006.

<sup>4</sup> Meeting between Corinne Manning and 'Gordon Michaels', 24 June 2006.

<sup>5</sup> Conversation between Corinne Manning, Ralph Dawson and Donald Starick, 31 July 2006.

<sup>6</sup> Ibid.

While living at Kew, residents were expected to adhere to institutional rules and obey staff commands. For example, Ralph was required to prove himself worthy and sign a good behaviour contract before being allocated a higher standard of accommodation than the dormitory in which he was living. He stated, 'I signed a contract ... [to] be good and not punch someone and swearing at someone.'<sup>7</sup> 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!

However, Ralph was not purely interested in the monetary aspect of participating in the project. His inclusion resulted from an interest shown in the project after watching his housemates record their stories. When I visited his unit at Kew and CRU, Ralph always spoke to me about life at Kew and offered his opinions about the institution. Ralph asked if he could be involved in the project 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 for the project. As he was unable to give informed consent Ralph's sister was approached to give consent on his behalf. It took nearly two months before the consent process was completed. On my weekly visits to Ralph's CRU he always asked me 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 in the project.

Our interview sessions have been extremely valuable and enlightening not only in regards to documenting life at Kew from a resident's perspective, but also recording the experience of moving away from large scale institutional care. Ralph openly spoke about issues such as the division of his dormitory between the 'small boys' and 'big boys', the unbearable noise that drove him 'up the wall', working as an artist and his desire to escape institutional life.<sup>8</sup>

By the time I started work with Ralph, I had been interviewing people associated with Kew for a year. I was very comfortable working with a variety of people, including residents. However, at the beginning of the project, I admit I was somewhat afraid of working with people with learning disability. I was not concerned about their actions, but of me saying the wrong thing, doing the wrong thing or unintentionally causing harm in any way. In order to prepare for the interviews, I consulted with members of our team who had experience working with people with learning disability, an academic in the field of social work, Christine Bigby, and communication expert, Hilary Johnson. I read the few institutional histories that include oral testimony and even fewer sources that explore the issue of conducting research interviews with people with learning disability. After reading these texts, mostly based on research in the United Kingdom, and completing some background research into the history of Kew Cottages, I commenced interviewing. Although 'professionally' prepared, I felt apprehensive about discussing two fundamental issues with residents - violence and abuse. I knew that in raising these issues, I could potentially trigger a traumatic

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<sup>7</sup> Interview between Corinne Manning and Ralph Dawson, 3 August 2006.

<sup>8</sup> Ibid.

episode for interviewees. Although this was a standard concern for the majority of participants, I was particularly worried about the impact on residents and whether I would recognise signs of distress.

My reticence in talking about violence and abuse with residents was compounded by interviews recorded with Kew Cottages' staff who recalled stories of wilful neglect, extreme violence and abuse. One staff member recollected:

MG: It wasn't uncommon for staff, almost as a sport, to goad a client against another client. Have you heard of the Kew salute?

CM: No.

MG: It's nothing to be proud of and it's not a good thing. You probably find a lot of people wouldn't want to speak about it, but I'll guarantee every single one of them would know what you're talking about when you say it.

CM: What is it?

MG: Residents who were scared basically and so when approached they cower and cover up and put their hands up, that was known around the place as a "Kew salute", but this is horrible. You would get that now, just by walking past certain people, whether they know you or not.<sup>9</sup>

Another staff member supported this viewpoint. He stated:

There was an enormous amount of bastardisation and bullying by the older boys to the younger boys ... People can sweep it under the carpet and say it didn't happen, but it was very real, and it was a problem.<sup>10</sup>

I was acutely aware that some of my interviewees were undoubtedly victims and possible perpetrators of this violent culture. I also knew of at least one interviewee who had been kidnapped from Kew, raped and sent back to the Cottages in a taxi with a bag of sweets. Before long she was raped again, this time by a fellow resident.<sup>11</sup> I knew that I had to ask difficult questions and try to gauge the residents' perspectives. In order to effectively manage this area of questioning, I formulated interviewing strategies that were designed to raise or discuss such issues.

I was fortunate that many residents recalled cases of violence and abuse without my prompting. When this occurred, I asked follow-up questions about the specific account being told and encouraged further exploration of issues in general. I was painstakingly careful not to ask leading questions or support situations where acquiescence may occur. If I needed to raise the issues I usually started with a broad question: 'Have you ever been hurt or injured at Kew?' Depending on the response, the discussion continued from there. If so what happened? Was anyone else involved etc.?

If the respondent answered 'No' then I asked if she/he had ever been ill. This question often prompted a discussion of medical treatment and hospitalisation and provided an

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<sup>9</sup> Interview between Corinne Manning and Michael Glenister, 15 November 2005.

<sup>10</sup> Interview between Corinne Manning and John Wakefield, 15 March 2006.

<sup>11</sup> Interview between Corinne Manning and 'Marian Cumberland', 29 June 2006.

alternate way of identifying situations where possible violence and abuse may have occurred. I also used other areas of discussion such as absconding and the person's associations with staff, residents, volunteers and others, to determine the sorts of relationships that existed between the interviewee and others at Kew. Through these avenues of questioning it has been possible to record cases of violence and abuse in a non-confrontational manner. If a resident appeared to be too distressed I diverted questioning to another area.

Clare Turner was the first person with a learning disability that I interviewed for the history. She was able to give informed consent to participate in the project and was very outspoken about her hatred of Kew Cottages. I was extremely worried about recognising and understanding Clare's facial, body and vocal expressions because of her physical disabilities. Her physical movements were severely restricted, while her facial and voice expressions were quite animated. In order to prepare and get to know Clare I met with her twice before our interview. During these meetings Clare told me *her* Kew story which was dominated by memories of abuse, violence and her struggle to leave the institution.

My challenge with Clare was not how I was going to raise these issues, but how I was going to manage the interview in order to investigate beyond the rehearsed stories while ensuring her welfare during our time together. I decided to use my professional instincts - if things became too heated, I would change the subject, and if this failed to calm the situation I would stop the interview. Immediately concerns raced into my head. Would my actions impede her right to tell her story in her own way? Would this approach restrict her voice and agency? Am I treating Clare in an unfair manner because of my own insecurities? Our first interview session resolved these matters.

Clare was admitted to Kew at the age of 3 years and was discharged at the age of 25. At the time of our interview Clare had been living independently in the community for over 20 years. I began the interview with some general questions about when and how Clare came to live at Kew. I wanted to slowly accelerate the pace of the interview by getting contextual information and gradually leading into areas of discussion that I knew Clare was passionate about. My efforts were thwarted by Clare's urgency to record her story. I decided to let her run with it, to record the story that *she* desperately wanted to tell. After one minute and thirty seconds she recalled:

CT: Sister Carr was very nice, but all the other carers, I can't remember many of the carers now, it's so all years ago, years ago, oh, they were really nasty.

**CM: How were they nasty?**

CT: They shoved me outside in the cold, they shoved me [outside] when it's pouring [rain], they've locked the door on the key, on the, people, I feel sorry for the people who used to live there.<sup>12</sup>

Even in this short exchange the tempo and pitch of Clare's voice drastically escalated. In an effort to calm the situation I asked questions about the rain and how many people lived in the ward. Then I continued with questions about her family. By

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<sup>12</sup> Interview between Corinne Manning and 'Clare Turner', 5 August 2005.

questioning in this manner, I was able to determine the dynamics of the interview situation – Clare’s responsiveness when being questioned, what the parameters were of her memory recall and how she used her voice to convey opinions and feelings in an interview situation. Ten minutes into the interview things became intense when Clare recalled being attacked by another resident:

CT: ...One day, when I was on my bed, I was on my knees, on my bed, doing the socks with the night duty lady and one girl come up and she had long hair, nice and long like your hair, and she come up and bit me on the nose right on my skin the whole lot.

**CM: What happened?**

CT: And then I, I was crying.

**CM: Did anyone help you?**

CT: Well the lady saw me there: “What’s wrong?” I go: “Well what’s going on?” Then she go: “Oh, look at you!”, she was, that she that girl was, I don’t know her name I think it was Marion, I don’t know her name now, I forgot, the girl now I’ve forgotten now who it is now. And gee they pushed me around so much in that place in Ward 30 and 39.<sup>13</sup>

Clare was very agitated, her eyes widened and her voice became high pitched and strained. So my next question was:

CM: What were you doing with the socks?

Now anyone who listens to this interview or reads the transcript would gasp with disbelief - here Clare’s discussing a critical episode in her life and I ask about socks! Having researched her background and prepared for the interview by meeting Clare beforehand, I knew that this was one of her rehearsed stories, I had heard it twice before. Her physical demeanour concerned me, and I wanted to know about work practices at Kew anyway, so I took the ‘sock’ opportunity to follow this lead. I was rewarded with a discussion about the work that Clare had undertaken at Kew. I returned to her story of being bitten and the issue of abuse at the Cottages several times over our one hour interview. It was apparent that by dispersing these discussions throughout our session and a follow-up interview, I was able to limit the emotional and physical distress felt by Clare. I found that first interview with Clare to be an incredible experience, a physical and emotional rollercoaster, I must admit I was exhausted when I left her house.

So, had I treated Clare differently or unfairly to other interviewees? Absolutely not! I gave Clare the same respect and consideration that I show to all interviewees. If she appeared distressed I calmed the situation down, I allowed her to talk about issues that she considered important and took the chance to probe other areas of interest afforded by Clare’s responses. In all of the interviews that I conduct, if I feel that a person really doesn’t want to talk about an issue or if they appear distressed I offer them the chance to change the subject or to stop the interview. My role as an interviewer is not to force people to share information or stories, but to give interviewees the opportunity to discuss issues in a supportive environment, with due care and consideration. My interview sessions with Clare reflected this philosophy.

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<sup>13</sup>. Interview between Corinne Manning and ‘Clare Turner’, 5 August 2005.

Working with people with learning disability for the Kew Cottages History Project has been a challenging, yet extremely rewarding experience. It has reinforced the basic tenets of good oral history practice - that in all interview situations establishing an environment of trust, understanding and mutual respect will result in positive outcomes for all participants. Unlike Ellery, I do not perceive the Kew residents that I have worked with to be 'children of the darkness'. I have found them to be engaging, insightful and entertaining people. As Ralph declared, 'I'm clever, I use my head ... I think positive ... I'm happy' .<sup>14</sup>

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<sup>14</sup> Interview between Corinne Manning and Ralph Dawson, 3 August 2006.