

‘IH 54 Rewrite’

Annie’s Story: The use of Oral history to explore the lived experience of a learning disability nurse in the twentieth century.

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Abstract

Oral history, in the field of learning disabilities has, exclusively, focussed on the lives of people who were detained in large institutions and hospitals for the mentally deficient or handicapped (1, 2, 3). Such work has been invaluable in providing unique and authentic insights into the lives of people with learning disabilities during the last century. It has also helped us better understand the impact of social policy and legislative change such as the introduction to the Mental Deficiency Act 1913 (4). However, little is known about what life was like as a nurse working the field of learning disabilities in the last century. The main aim of this paper is to present analysed data obtained by using the oral history approach to support and, or, challenge our current knowledge of learning disability during this time. As such it presents a unique contribution to our knowledge of the history of learning disability nursing in the UK.

Introduction

Oral history has developed from the more traditional forms of collecting and recording historical events. In the past 'history' was the preserve of historians, often men, collecting data such as births and deaths, or, events such as wars, or memoirs of the 'great' and the 'good'. This information was in the keeping of the powerful, and contained little of the life of the 'ordinary man'. The focus was usually political and wars, reigns and dynasties demarcated the passing of time (5).

Within nursing, approaches to researching nursing history have adopted a similar approach. This has often involved studying 'significant' events such as the forming of professional groups, and the work of influential figures such as Florence Nightingale (6). This approach comprises less narrative, and more cataloguing of events. Particular examples for the field of learning disabilities nursing is extremely rare, but still tend to catalogue events (7, 8). Whereas undeniably such works contribute in providing an overview of the provision of care, they are unable to illuminate the lived experience, in a way that oral history is able.

Oral history provides researchers with opportunities to capture the views and experience of people at all levels of society, and within groups enabling the researcher to more fully understand what day to day life was like for the interviewee, and to some degree, empathise with their situation. Examples of such work can be seen in the contribution of Potts & Fido (9), which poignantly captured the experience of people with learning disabilities who were institutionalised. Similarly Atkinson et al (10) have documented the personal recollections of women with learning disabilities by enabling them to tell their 'stories'. Such individuals, in common with other

ordinary people, tend not to bequeath a legacy of documentary evidence unlike the rich and famous who leave diaries, photographs and mementoes, and who may wish their version to be the one that is recorded in perpetuity or in their own image (11).

It has also been noted that in the last thirty years many institutions and hospitals have closed and in doing so, official documents have been destroyed or mislaid (Atkinson et al 12). Even when evidence does exist it is usually in the form of professional paperwork such as medical records, and these capture nothing of the life of the people who worked and lived in such places.

Oral history has been used as a tool to recall events for many centuries. In pre-literate societies it became the standard way in which the passage of time was recorded. Stories, rhymes and songs have been used to great effect in reminding future generations of the past, or even for passing on the genealogical lines of tribes (13).

This is not to argue that oral history is the only or indeed primary method to use when undertaking historical research. Rather, it is been proposed that a number of methods be employed to gain information from a variety of sources, which can be pieced together to reconstruct particular periods in history (14).

It has also been proposed that oral history, unlike the traditional research of a lone historian, lends itself to group exploration and teaching (15). Group approaches to the shared experiences are successfully evidenced in recent publications where several researches and several participants have explored the history of learning disabilities see for example, Atkinson et al (16) and Atkinson et al (17).

The Study

The context for this study lies in

The subject-Annie

Annie was born in Eastfield in 1921; she was the only child in an extended family in which her mother helped her disabled grandfather run the family business. Absences from school, due to ill health, prevented Peggy from entry to the 11+ examination and any chance of a scholarship. Subsequently, at the age of fourteen her schooling came to an end, and she left behind her aspiration to be a children's nurse and to *'push the prams in Hyde Park'*.

However, her desire to work with children never left her and was to feature throughout her working life in different forms. After leaving school aged 14 in 1935 she was employed by a family at a vicarage looking after their children and helping the cook. She describes this as an *'ordinary domestic kind of life'* and indeed, at the time it was common for girls and young women to work in the service of a family. Later, she went to work in a similar capacity in a neighbouring village Asbury, and whilst there became engaged in work with *'physical people, sick people in beds – you know, in wards'*.

However, in 1938 she had returned to the family home in Eastfield and was informed that there was a vacancy at the Weston Institution should she wish to apply. Annie subsequently wrote to the Matron and was offered a nursing assistants post, without an interview, which she commenced at 6pm on November the 11th 1938. Within a couple of years Annie had taken her exams and had become a Charge Nurse. It is

notable that Mental Deficiency Nursing, had by this time, become a separate part of the Mental Nurses Register (18, 19) following the Nurses Registration Act 1919 (20).

In 1945 World War II ended and Annie married Jack who, having started as an office boy, became the Hospital Administrator. Rose left work in the same year and returned in 1955 when the youngest of her three children was seven years old. She worked on both the children and women's wards at the hospital and retired in 1981 aged 61. She had worked at the hospital for a total of 33 years and, in her own words; *'never regretted one minute of it'*

The Interviews

Firstly, contact was made with the informant that was followed by a letter explaining the role and remit of the research and researcher; simultaneously consent was sought for her to participate in the interviews. After informed consent had been obtained two semi-structured interviews were undertaken. In order to make sure the interviewee was at ease, and not unduly stressed the interviews were conducted in the privacy of her own home, and in an informal and relaxed manner. The interviews were taped recorded using a high reproduction quality 'Marantz' tape recorder. There were no communication difficulties and the interviewee presented as an articulate speaker who was comfortable with the interviews and tape recording. It has been noted that most people forget about the presence of the tape quite quickly (21). In order to limit the risk of restraining the conversation, a questionnaire approach to interviewing was avoided. Instead, recollection was encouraged by use of semi-structured interview using open-ended questions in an attempt to yield more rounded and detailed responses. This approach has also been successful when working with people who

may be susceptible to acquiescence or, a desire to conform to the expectations of the interviewer (22). As the researcher and informant were both nurses there was a need to ensure loaded or leading questions were not used such as ‘the nurses workload was terrible wasn’t it?’ The researcher was also mindful to ensure that full explanations were sought, if a response was incomplete rather than ascribing their own personal meaning to an event. A series of questions were developed to explore the interviewee’s personal and professional life, relationships and the impact of health and social policy upon her working life. For the purposes of anonymity, pseudonyms have been used to replace names and places within the study. Prior to the interview significant historical inquiries were undertaken to map out important events, professional, political and legislative that occurred during the timespan of the participant’s career along with those that shaped care provision before and after. This provided a verifiable ‘catalogue of events’ against which the reliability and validity of the informant’s recollections and interpretations of events could be assessed. These ‘events’ are where appropriate included in the analysis and discussion sections of this paper.

In addition to the interviews, the researcher also gained information from various sources such as photographs, pertinent literature and policy documents. This approach is supported by Atkinson et al (23) who have proposed that it enhances both validity and reliability of interviews by collecting objective records to check against subjective memoirs. It is broadly comparable to triangulation methods more generally used in qualitative research to enhance claims of validity (24).

During the interview the interviewee offered extensive documentary evidence to support her recollections that included photographs and historical data. After taping the interviews, each lasting over an hour, data was transcribed and analysed for emergent themes, which then formed headings under which data has been organised. Tapes were labelled and securely stored.

Analysis and discussion

The tapes were listened to and transcribed verbatim and then subjected to content analysis. This enabled us to develop five theoretical categories that we believe describe the lived experience of Annie as a learning disability nurse until her retirement in 1981. It is worth pointing out that we have woven into this analysis primary sources of data and other credible historical commentary that reinforces the credibility of Annie's story and that this adds considerable weight to the validity of our findings and analysis. Text that appears in *italic* is that of Annie's and represents verbatim script that has been compressed for the purpose of this paper. It can be seen that the terminology used to refer to people with learning disabilities changes within the text this represents the temporal dimension of learning disabilities and in a sense traces the changing attitudes toward this group of people.

- **Segregation from society – the rise of the institution**

In 1938 the Weston Institution, in which Rose was to spend the whole of her working life, was opened. The 'Board of Control Certificate' only allowed for the provision of female adults and male children. The fact that male adults were not initially admitted is not unusual for this era, as the prevailing purpose of colonies, asylums and institutions was to prevent the procreation of the mentally deficient. This was

achieved by the segregation of the sexes, so even where male and female adults were at the same hospital they were housed on separate wards (25, 26, 27).

Protecting the nations gene pool was deemed to be paramount and the response was to identify and certify those who presented this 'threat' to the moral and intellectual rigour of society (28, 29, 30). This idea stemmed from the eugenic movement at the beginning of the century and was supported in the report of the Royal Commission on the Care and Control of the Feeble-minded 1908 (31) and the resulting Mental Deficiency Act 1913 (32).

It was proposed by the eugenicists that this group of people were a danger to society due to the familial characteristics that linked them with moral degeneracy, criminality, promiscuity and a propensity to procreate in greater numbers than 'normal' people (33, 34, 35). It would seem no coincidence that many of the Mental Deficiency Institutions including Weston, initially began as workhouses or inebriate reformatories (36). Their later use for people with learning disabilities firmly placed them in the same category as those deemed by society to be immoral and either unable or, unwilling to work (37).

Moreover, during the 1930's there was a rigorous campaign waged for the voluntary sterilisation of this group in society, and it was recommended by the Brock Report in 1934 (38) that legislation be provided to enable this did not happen. However, the eugenic principle was to give rise in later decades to compulsory sterilisation policies in countries such as the USA and the killing of disabled people in Nazi Germany (39, 40).

The invention of the IQ test in 1908 and the passing of the Mental Deficiency Act in 1913 allowed for both a means to test and a means to legally detain people accordingly. People were classified 'low grade - idiots and imbeciles' or 'high grade – feeble-minded and morally deficient' (41). This created a marginalised group in society and placed barriers between them and so called '*normal*' people, including staff such as Annie who said she eventually '*got used to them*'.

The institutionalisation of people who were 'feeble-minded' is supported by Annie's experience of working on a ward for women who '*were just sort of slightly mentally disabled and epileptics and things like that*'. Moreover, in common with residents at other hospitals (42) Annie recalls that some '*ran away*' from the hospital in response to their predicament.

The plight of women during this time in history is a theme picked up by Walmsley (43) who has noted that in a study of one area, Bedfordshire, women were four times more likely to be assessed as requiring admission to an institution than men. Moreover, it was also recognised that sexual behaviour was a major factor in determining admission (44, 45). Evidently the institution in which Annie worked reflected this trend in its provision of 110 adult beds for women only.

Carpenter (46) has noted links between learning disabilities and the Christian Missionary movement and religious themes can also to be seen in the work of the female patients who were often employed in the hospital laundry in order to metaphorically '*wash away their sins*' (47).

Furthermore public opinion was even noted to challenge those who chose to work with people with learning disabilities. As Annie recalls;

'Well I think a lot of people when they got to know us were alright about it but I think there were quite a few people who used to think, well you know, what the heck do you want to be with them lot for? - They're all crackers'

This kind of opinion did not appear to deter Annie from her work, however, it has been noted that some nurses working in mental health had felt a 'stigma' associated with their job and were embarrassed to talk about their role to people outside the hospital (48).

- **Rules, Regulations & Routines**

The place where Annie was to work, Weston Institution was not alone in the area. It was managerially linked with two other similar local establishments that shared the input of one psychiatrist Dr Smith. This 'network of institutions' is a situation that was replicated in other rural parts of the country such as Somerset (49). Moreover, at the time most institutions were under the management of women (50), female matrons were commonplace and only 23 of the certified state institutions had medical leads in 1937 (51).

'There was a Matron and a Sister in those days you see and you had to make sure you did exactly what the rules were and a lot of it depended on the people in charge of the ward. Now when I was in charge of the ward I'm afraid I had my rules and regulations and they had to be carried out exactly as they should be'

In the above passage Annie describes how the hospital was run when she entered nursing in the 1930's and how she subsequently carried on the tradition when she qualified and became a Charge Nurse. This type of hierarchical structure and adherence to 'rules' has much in common with the religious and military origins of nursing (52) and the desire for order and uniformity in practice and appearance. As Annie states when asked how she felt about her wearing a nursing uniform

'as far as I was concerned it was, well it seemed to me to be the thing to do because if that was what you wanted and if you was a nurse and you wanted to be one and I mean, lets face it, how many other people wore uniforms? I mean when you was in the forces and things like that'

A formal connection to organised religion was a strong feature of institutional life and in keeping with the 'cloistered' nature of many hospitals, it was not unusual for them to have their own chapel (53). Those that did not have such facilities would take patients, as in Annie's case, to the local church as she describes;

'we used to walk up to Weston to go to the service and walk back to the hospital, it was part of life'.

These conformist traditions manifest in many ways within the institutions and are recurrent themes in Annie's descriptions of work with emphasis placed on obedience as the following comment illustrates;

'I must admit I never had any problem with the staff there was only the odd one or two over the years that argued with me about doing things but I said no, if you don't like it just go to the office and ask to be moved if you don't want to follow my rules'

In later years just prior to Annie's retirement in 1981 she was to have problems with a qualified staff who Annie noted;

'objected to the way I did things and the time which I did them, I mean, to me, if something was to be done it was done at the same time, if it was an important thing and dressings and baths and things like that it was done on a rota and done and all the patients were all fixed and knew what to do and I wasn't changing the programme, it had been like that for the last 5 or 6 years'.

The maintenance of regime was typical of such hospitals and contributed to the institutionalisation of the patients, which was described in the work of researchers such as Barton (54), Goffman (55) and Morris (56). However, we should be mindful of adopting a superficial view of this situation and ensure that the societal and environmental influences of that time are recognised. Whilst there were undoubtedly a number of staff who abused and mistreated the patients, subjecting them to inhumane and degrading practices (57, 58, 59, 60). Equally there were many nurses who tried to provide care for large numbers of people with a very small number of staff.

It is easy, but simplistic, in our desire to rightly close such hospitals, to see nurses as the architects of this system. However, with hindsight, the way many ward staff

managed to get through such workloads was to adopt a traditional task orientated model, that was similarly applied to other branches of nursing.

Annie confirms the problematic nature of providing individualised care when she describes the women's ward as been between 40-45 beds with a shift allocation of 4 staff including her. This description is supported by the work of Thomson (61) who found that in 1939 the staff to patient ratio on female ward areas was on average 1:11.8.

The 'overwhelming inadequacy' of the staffing allocation can be verified by the research of others such as Ryan & Thomas (62). Annie noted that some relief in the number of residents to care for was gained during the day as '*some of them used to go to the training unit*'. However, it has been noted that this usually meant that the 'most difficult' people were still in the care of the nurses as they were left behind on the ward (63).

Staff shortages are also evidenced in the Wood Report (64) that noted the crisis in recruitment and retention of nurses in all branches. Indeed, a policy of employing nurses from abroad to work in learning disability services was pursued in several hospitals (65). Correspondingly, Annie met her lifelong friend Clara at Weston when she came from Germany to work at the hospital after the war.

In later years, Annie also recalls how the Matron of the hospital, whose role she subsequently describes as been quite matriarchal, was replaced by nursing officers;

'but of course as you know we stopped having women and got men you see, and some of the men that we had, particularly the last but one that we had was really first class'

Moreover Annie remembers;

'they had a new boilerhouse man in charge of there and his wife was trained and she took over as the matron and then they went to having the men nursing officers'.

Both these comments by Annie illustrate her views and recollections around the early 1970's at a time when the NHS was beginning to implement the recommendations of the Salmon Report (66). This report, which reviewed senior nursing staff structure and made many changes but in particular, ended the role of 'matron' and introduced different grades of nursing 'officer'. Again, it is evident that nursing and military titles for example 'officer' are inter-linked, however what is perhaps most fascinating about these comments is Annie's emphasis on gender. She clearly equated Matron as being female and the Nursing Officer as male. Furthermore, she implied that it would not have been conceivable for the nursing officer to be a female. This is illustrated in her views that the hospital '*stopped having women*' and '*went to having the men*'.

- **Relationships**

Recently published personal recollections of former residents of hospitals such as Weston offer us insights into the often long- standing companionship between some of the nurses and residents. Mabel Cooper a former resident of St Lawrence's Hospital in Caterham remembers making friends and sharing conversations with a nurse called Eva (67).

The problems previously outlined in regard to the hospitals staffing resources undoubtedly affected the relationship between nurses and residents and is echoed across the whole of Annie's career. However, it was particularly obvious when the hospital took the residents on their holidays, as Annie describes

'Well there would be roughly 30 or so because we had a coach load used to take us and then after we'd been there the week they used to come and pick us up...there would be four staff'.

Despite such problems trips to the coast were looked forward to (68, 69) and as Annie recalls they gave time to *'sit down and talk quite a lot'* to residents.

The opportunity for residents and staff to get to know each other seems to have been valued by Annie. She recalls the day in 1966 when the first male residents arrived to live at Weston Hospital and that she;

'didn't know quite what sort of things they expected or what they were like but, after a week or two we got to be good friends'.

This quote may appear to indicate not just a significant relationship between Annie and the men but also an acknowledgement of their 'expectations' of her.

Moreover, another revealing memory illustrates how the task-orientated culture of the hospitals dictated the order and importance of work as Annie remembers the women residents initiating conversation;

'they always used to come and fetch me because if I hadn't any work in the office I used to go and sit in the room with them you see and talk to them'.

Annie's experiences when working with the women residents were, to some degree, similar to those when working with the children in that they would be left behind on the ward and she would sit with them and talk to them. During the 1950's and 1960's children with learning disabilities did not attend any form of school as they were deemed ineducable. However, the 1970 Education Act (70) introduced the principle of education for all and was at the start of a legislative process that eventually saw the responsibility for children transfer from NHS to Local Authority.

For Annie working on the children's ward was the highlight of her career;

'I never regretted one minute of working at all but I must admit, if I'm being honest, working with those children was my top priority, I loved those kids'.

- **Work & home**

Annie met her husband at the hospital when he was an office boy. He later became the Hospital Administrator and they lived, with their 3 children in the grounds of the hospital in a building that had been used previously, when it was a workhouse, to house vagrants.

This blurring of the private and work life may seem somewhat alien to many nurses now however, Annie worked in an era where 'living in' was a pre-requisite of training and where the Matron was a matriarchal figure. Indeed, on the day matron married, she returned to Weston Hospital and had a formal photograph taken with the nurses

‘in her charge’ in full uniform, and herself in her wedding finery. It would seem evident that along with the ‘professionalisation’ of nursing has been a separation of home and place of employment.

Annie also demonstrates in her recollections how, despite having a young family, she defined her own sense of ‘duty’,

‘yes, I mean they meant the world to me...when I went back to work I never had a Christmas Day off at home I worked every Christmas DayI said no, I can’t leave my patients on Christmas Day’.

‘and they (residents relatives) always brought me cards and they always thanked me and invited me to the funerals.....and said thank you for all I’d done for them....and I just said ‘oh, I’ve enjoyed what I’ve done and I didn’t say that was my job because I didn’t think that was the right thing to say...I mean, I didn’t just do it because of that, I mean I did it because it was part of life and when we moved down to the hospital, I mean my kids used to come up on to the wards to me. They got involved in the work.....’

- **Changing ideology**

Annie’s recollections clearly illustrate the regimentation of institutional life and lack of resources in service provision. However, despite these circumstances she revealingly describes what unacceptable care would look like, specifically;

'for not treating the patients as they should be, not talking to them as they should be and not making sure that they were always comfortable and not treating them as a human being, just leaving them to one side'.

Commentators have substantiated this statement by making reference to a similar comment by another learning disability nurse in a longstay hospital (71). Moreover, they have noted that it is indicative of the fragility of the patient's status in such places that the nurse feels it is necessary to reinforce their humanness.

However, this would seem to acknowledge, at least on the part of Annie, that the patients were human beings with the same basic needs as anyone else. This is an interesting comment on the part of Annie as much of the scientific literature and legislative documentation of the time uses dehumanising descriptions of people with learning disabilities such as idiot, imbecile and low grade (72, 73).

When Annie began her career the institutions were the responsibility of the Local Authority and their status as 'hospitals' was not conferred until 1948 when the legislation contained in the National Health Service Act 1946 (74) was enacted. Subsequently, the 'medical' model was confirmed as order of the day along with the development of professional roles within the field (75).

Indeed, Annie's evidence in regard to her nurse examination depicts a reductionist view to the needs of people with learning disabilities, which required her to;

'learn all about the body and all about the bones and all about the internal ones and all about the circulation and all about breathing'.

However, by the late 1960's and early 1970's a number of Department of Health Reports enquiring into the 'scandalous' care for people with learning disabilities were published (76, 77, 78). These reports observed a lack of government investment and resources and became a catalyst for changes, which were championed by Richard Crossman the then Minister for Health (79).

Also, within the 1970's other significant events occurred that were to interlink and completely change the ideology and direction of care for people with a learning disability. As far back as 1951 the National Campaign for Civil Liberties decried the plight of people in long stay hospitals (80). Indeed, they are recalled by a former patient as being instrumental in assisting him to leave hospital in 1955 (81).

In 1971 the civil rights of people with a learning disability were internationally acknowledged when the United Nations published the Declaration on the Rights of the Mentally Retarded (82). In the same year the pressure group Campaign for the Mentally Handicapped (now Values into Action) was formed and the White Paper Better Services for the Mentally Handicapped (83) was published.

In the following year, Wolfensberger published his seminal work on the principle of normalisation (84). Later in the same decade the Jay Report into 'Mental Handicap' nursing and care was published (85), and advocated a new caring 'profession' and the

right of people with learning disabilities to enjoy normal patterns of life as an individual in the community.

This series of events culminated in the subsequent, albeit slow, closure of thousands of beds in hospitals for people with learning disabilities toward a move to care in the community and the pursuit of an 'ordinary life' (86).

By this time Annie was due to retire and despite the rhetoric and promise of a better life, changes for people with learning disabilities were still problematic. The change in government from Labour to Conservative in 1979 was the beginning of the Thatcher' years and the drive for economy, efficiency and effectiveness in health care (87). The government report Progress, Problems and Priorities (88) gave details of the changes since the 1971 White Paper Better Services for the Mentally Handicapped and, as suspected, targets that were set had not been met on time. However, over the next two decades most hospitals for people with learning disabilities did close.

To conclude, for Annie these years just before her working life ended signified a time when her '*friends*' left the hospital and moved away from the local area. Indeed, as she recalls, her memory of the loss of one former resident even after her retirement and formal links with the hospital severed, was poignantly significant;

'I was a bit upset, in fact I cried a little bit because I used to always write to her at Eastfield and I used to get a card from her at Christmas time and then they packed up and went to Wales and the people in charge never sent me the address'

Conclusion

The outcome from this oral history interview has been a unique recollection of one nurses lived history of working in an institution for people with learning disabilities. The account did not contradict what is known historically through written records; indeed it has enhanced and elaborated on them. Whereas official records have provided documentary evidence of facts and figures, Annie's recollections, through the oral history method, have provided detail of the authenticity of daily routines, relationships, home life and care giving. The strengths of oral history lies in its ability to generate knowledge and provide insights of day to day life, by providing 'historically minute detail' (89). The limitations of this approach include the risk of misrepresentation, distortion and omission and the time consuming nature of transcription. However, we believe that by triangulating Annie's accounts with various other sources of information, as we have done, made it possible to corroborate her personal account. Also work already undertaken using such approaches has proved it can provide alternative and at times, painfully honest and authentic accounts of history (90, 91). It can also, as in Annie's case offer contemporary nurse practitioners an amazingly personal window into the history of learning disability nursing.

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