

From changeling to citizen: learning disability and its representation in museums

Kathy Allday*

Knaresborough, Yorkshire

Abstract

This paper examines why museums, both currently and historically, have excluded material relating to people with intellectual impairments. The national picture is examined briefly before the focus shifts to three UK museums in York, Leeds and Colchester where curatorial attitudes to including and presenting material on learning disability are compared and contrasted. Curatorial anxieties about the subject, a lack of national guidance on how to address learning disability in museum collections and displays and the elusive nature of available sources of material appears to discourage museums addressing the issue. Nevertheless, a few examples show that with organizational and professional commitment and the adoption of facilitative and consultative approaches, museums can present the history of learning disability in exciting and thought provoking ways that challenge pre-conceptions about intellectually impaired people. Given museums' responsibilities under the Disability Discrimination Act (2005), the significance of the social inclusion agenda and calls for new museological practices, there has never been a better time for museums to re-evaluate their approaches to learning impairment.

Key words: learning disability, representation, museums, inclusion

Introduction

The changing definitions of difference constitute the history of 'mentally handicapped' people. These definitions have always been conceived by others, never are they the expression of a group of people finding their own identity, their own history (Ryan 1987: 13)

In recent years, museological literature, policy and practice in the UK has begun to address the issue of disability and its representation in museums. This has been influenced in part by calls for more enlightened socially inclusive working practices by DCMS¹ (2001), RCMG², (Sandell 2004, Delin 2006) and curatorial practitioners (for example Marwick 1995, Bardgett 2001, Fleming 2002, Kavanagh 2002). In discussions about disability representation, however, there has been little analysis of the challenges of consulting people with intellectual impairments and the various means available to represent their lives and histories in museums. This paper attempts to shed some light on this little documented issue.

There are 210,000 people with severe learning impairments in England and about 1.2 million with mild or moderate learning impairments (Department of Health 2001: 2). The 2005 Disability Discrimination Act (DDA) places duties on public authorities, including museums to address the needs of intellectually impaired people along with all other disabled people, and yet museological policy has neglected this area.

Buried in the Footnotes (RCMG 2004) and a survey of disabled people in Colchester (Delin *et al.*:2006) both provide an insight into attitudes to disability presentation from a curatorial and disabled person's perspective respectively but fail to specifically address how the lives and histories of people with intellectual impairment can be meaningfully presented by museums. Although there are some parallels with other impairments and mental illness, the history of

learning disability reveals difficult stories about society's intolerance and fear of a group of people powerless to defend their civil liberties and rights to equal citizenship.

As a parent of a child with Downs Syndrome I became immediately aware of the labels and prejudice associated with a learning impairment that made my daughter different from the other children in the local mainstream school. My daughter is now 21 and thankfully attitudes are changing, her individuality is valued and the contributions she can make to society are beginning to be recognized. If she had been born several decades earlier, our lives would have been very different. It was thinking about how people with intellectual impairment had been treated in the past that provided the starting point for my own research for my MA dissertation at the University of York. I wanted to find out if the potentially thought provoking story of learning disability was a subject museums were addressing.

This paper summarizes the findings of my research that explored the challenges and opportunities that museums face if they decide to present material on learning disability history. An overview of the story of learning disability sets the issue in its historical context and highlights the material available on the subject. The literature and government policy on difference and disability which sets out the arguments for representing difference is then discussed. This reveals that there is a vacuum in policy guidance for museums. A few, but certainly rare, examples of best practice are provided that highlight how museums can sensitively engage with people with intellectual impairment to produce enlightening displays about learning disability history. Finally, the paper reveals the results of the research I conducted at three case-study museums where ten practitioners were interviewed to assess curatorial attitudes and current and potential methodological approaches to representing material on learning disability. My research aimed to explore the scope of existing collections to present the history of intellectually impaired people in a meaningful way and to ascertain whether there were opportunities to be developed and obstacles to overcome. The impacts of the 2005 Disability Discrimination Act, social inclusion policy and the new museology agenda on museum attitudes to including material on learning disability were also assessed.

Mongols, changelings, morons and defectives: English society's historical responses to intellectually impaired people

In order to understand the absence of material on learning disability from museum collections and displays historical as well as contemporary factors need to be considered. Reference has first to be made to the political marginalization and physical exclusion of people with intellectual impairments from English society and the language and methodologies used by society to categorize, marginalise and disempower them. This provides the historical context against which the social exclusion of intellectually impaired people from England's cultural heritage can be assessed and understood.

Historically intellectually impaired people have been categorized and 'graded' by education and medical professionals and government agencies in order to determine their care and treatment. Almost everyone suffers from impairment as a result of the ageing process, but the labels attached to intellectually impaired people have largely been the result of cultural categorization (Shakespeare 1997), resource availability (Oliver 1990, Barton 1996) and medical intervention (Borsay 2005, Ryan 1987). The history of learning disability in England from medieval times to the present day is one in which societal attitudes have fluctuated from ridicule, fear and loathing, to pity, charity, tolerance and understanding. Gleeson argues that impairment was accepted and commonplace among medieval peasants – and so 'disability occupied a social space distinct from yet embedded within the general terrain of everyday life' (cited in Borsay 2005: 13). In some quarters however, 'handicapped' children were regarded as changelings, who came from a sub human underworld of fairies, elves and demons in exchange for a stolen human child (Ryan 1987, Shakespeare 1997). Giving birth to a changeling was grounds in Europe for being burnt as a witch (Ryan 1987: 88).

As the industrial revolution gathered momentum, the lives of intellectually impaired people and society's perceptions of them changed dramatically. In an urban capitalist economy, the speed of factory work, time keeping and production norms were a complete change to the slower, more flexible methods of working into which intellectually impaired people had previously been integrated (Ryan 1987: 101).

Both governmental and the wider society's concern about the collapse of family life as a result of industrialization led to the construction of workhouses, asylums, and later mental deficiency hospitals to accommodate the elderly, impotent or disabled poor. Barnes (1996: 56), tracing the gestation of the disability category to the nineteenth century, associates it with the individualization and medicalization of the body, with the systematic exclusion of people with impairments from mainstream community life and with the emergence of Social Darwinism and the Eugenics movement. Francis Galton, Darwin's cousin, coined the phrase *eugenics* in 1869 and was influential in starting a movement which saw disabled people as a threat to British and European society because of 'racial' degeneration. The Eugenics Society demanded the sterilization and segregation of 'defectives', their scare mongering reinforcing myths about the genetic links between 'mental' impairments and crime, unemployment and other social ills (Barnes and Oliver 1998: 33).

In the nineteenth century philanthropic charity, education and medical authorities vied for control over how intellectually impaired people should be cared for. Educationalists emphasized the potential of people with intellectual impairments and concentrated on similarities with the rest of society (Ryan 1987). Medical professionals emphasized difference and the need for segregation. In 1913 the *Mental Deficiency Act* introduced compulsory certification for people considered to be 'mentally defective'. Doctors were relied upon by the Mental Deficiency Committees administering the Act, to identify and categorise 'defectives' which would result in their supervision in the community or their forcible removal from families and incarceration into mental deficiency colonies (Ryan 1987, Barnes and Oliver 1998).

Doctors and educational psychologists continued to diagnose 'high, medium and low grade' 'defectives' until the late twentieth century when increasing awareness of institutional neglect of people with intellectual impairment began to influence changes in government policy. Frank Thomas, a nursing assistant in a large 'subnormality' hospital in 1972 kept a diary that was incorporated into Ryan's *The Politics of Mental Handicap* (1987). The diary details the demeaning objectification of patients:

At arrival all semblance of individual personality was removed – all personal possessions including clothing were not permitted and daily life was controlled by rules and regulations, rather than personal choice. (Ryan 1987: 31-41).

Thomas describes degrading practices such as being forced to use lavatories without doors, queuing in the nude for a weekly bath, wearing other people's dirty underwear because of clothing shortages and being forced to eat cold meals in silence every day (Ryan 1987: 31-41).

The neglect of people with intellectual impairment by residential and medical institutions was mirrored in the educational field. Binet and Simon, French psychologists and originators of the IQ test, maintained that 'mental defectives' were ineducable. The IQ test, which assumes a continuum of intelligence from subnormal to super-normal, categorized degrees of 'mental deficiency', and was used by educational psychologists to identify people with intellectual impairment throughout the twentieth century. Whereas Seguin, a nineteenth-century French educationalist, had argued that intellectually impaired people would benefit from education, eugenics influenced an increased fatalism. From the late nineteenth century until the Second World War, the 'feeble minded' (formerly 'morons, idiots and imbeciles') were denied a proper education (Potts 2000, Borsay 2005).

In the late 1960s, *The News of the World* and *The Guardian* newspapers both exposed appalling conditions in two mental 'sub-normality' hospitals: Ely Hospital and Harperbury Hospital respectively (Ryan 1987: 117). Further scandals were to follow as more nursing staff 'blew the whistle' about hospital conditions (Ryan 1987). As public pressure mounted, a series of government reports recommending reforms and legislation followed, culminating in the closure of all 'mental subnormality' institutions by 2003 and the introduction of 'care in the community' and the Government's White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001).

The language of government is becoming more inclusive towards people with intellectual impairment (Department of Health 2001) but prejudice still remains. Current policy still emphasizes the principle of 'normalization' which Barnes *et al.* (1999:74) criticize because it is dominated by professional expectations of change to 'normality', and does not place value on

the intrinsic worth of intellectually impaired people. If those responsible for the care of people with intellectual impairment still use prejudicial language towards them, it begs the question - can museums be expected to become fully enlightened towards people with intellectual impairments?

Countering prejudice and the role of museums

The origins of collections and the founding purposes of traditional museums make the presentation of formerly excluded histories challenging. The limited remit and scope of some material collections have left a significant historical legacy for museums today. Natural history and antiquarian collections bequeathed by wealthy benefactors, collections amassed as a result of colonial conquests and bequests from aristocratic families who wanted their history and their heritage preserved tell a one-sided story of England's social, political and cultural history (Walsh 1992, Hooper-Greenhill 2000). The new museology literature has highlighted how such collections, inherited when emphasis was placed on extolling the virtues of the great and good, contrast with the dearth of material relating to the history of disabled people and other socially marginalized groups in England (Dubin 1999, Sandell 2007a). During the late nineteenth century, when many museums were being established, people with learning impairments were being incarcerated in workhouses and asylums, and were among a number of marginalized groups who were blamed for many of society's ills. Not surprisingly the lives of people with learning impairments were not only considered at the time insignificant, but abhorrent – totally unsuitable material for museum collections.

There are consequences if museums do not address the history of learning disability. Many sociologists and social policy analysts argue (Barton 1996, Apple 1993, Atkinson *et al.* 2003) that historically informed understanding of the past is an essential precondition to change and empowerment. Apple (1993) refers to the danger of a collective memory loss. The possibility of the history of learning disability institutions being forgotten is a real one. My own research on the history of Leeds Union Workhouse and its associated 'Imbecile' and 'Idiot' wards revealed that their demolition and conversion, like many former learning disability institutions, coincided with the destruction of historical papers relating to former patients and management regimes. Sociologists, local historians, museum and archive service professionals can play an important role in stemming the loss of this material.

By addressing the histories of people with learning impairments, the conditions in which they once lived, the political and legislative, social and professional influences which shaped these conditions, society can begin to understand how people's identities and places in society have been shaped over time (Barton 1996: 11). Greater understanding may change attitudes and help to address the significant amount of prejudice against people with intellectual impairment that still exists in our society (Priestley 1999, Atkinson *et al.* 2003).

Learning disability and current museological discourse

In order to understand the relationship between museums and intellectually impaired people, it is necessary to say something at this point about the discourse generated by the new museology literature and social inclusion agenda.

Early 1990s criticisms by Horne (1992: 70) and Walsh (1992: 129) of traditional museums, which targeted their elitism and narrowly defined collections policies, remain pertinent today. Traditionalism and displays that strive to emphasize harmonious, consensual heritage are obstacles to representing difference in museums (Walsh 1992, Smith 2006, Sandell 2007a). Presenting history that avoids negativity and controversy is criticized in the literature for lacking depth, perspective and integrity (Walsh 1992: 29, Abram 2002, Duncan 2003) and is the antithesis of where museums need to be if they are to address the real lives, experiences and achievements of people whose histories may be uncomfortable and controversial.

Museums have been criticized for avoiding uncomfortable histories in the mistaken belief that the public can not bear the 'truth' (Abram 2002: 130) but Bardgett (2001), Marwick (1995), Abram (2002), Landzelius (2003) and Duncan (2003) amass significant evidence to the contrary. Positive reactions to the Holocaust Exhibition presented by the Imperial War Museum

in 2000 provide just one example of this. The exhibition used propaganda films put out by the Nazis to portray their treatment of disabled people, including those with intellectual impairment (Bardgett 2001: 57-60) and resulted, for example, in one visitor commenting:

I am leaving this stunning exhibition a different person from when I came in.
Everyone should visit it. (cited in Bardgett 2001: 59).

The 'new museology' debate has encouraged changes in traditional museum practice and the development of new social history agendas. Former dominant narratives about great men, great wealth and great deeds (Dubin 1999) and national pride (Horne 1992) have changed to the local and the personal (Smith 2006, Claval 2007); from the consensual to the dissonant (Ashworth and Tunbridge 1996). Curators increasingly recognize that multiple representations and multi-voice makes museums more socially and culturally relevant (Ashworth and Tunbridge 1996, Hooper-Greenhill 2000). The literature calls for museums to take social responsibility for revealing previous injustices and to rewrite the histories of slaves (Duncan 2003), working class labourers (Smith 2006), people of colour (Hayden 1997), women (Hooper-Greenhill 2000) and people with disabilities (Shakespeare 2000, Delin 2002, Sandell 2007a). It has been well documented that authoritative and traditional curatorship needs to be replaced with more facilitative approaches if formerly excluded histories are to be addressed by museums (Marwick 1995, Bardgett 2001, Kavanagh 2002).

In tandem with changing museological methodologies, the last ten years have witnessed the radical re-writing of official cultural heritage policy with inequality and poverty at its centre. As well as being educational, museums are now expected to promote social inclusion, tackle deprivation and disadvantage and reach the widest possible audience (Sandell 1998: 403). Government policy on social inclusion (DCMS 2005) advocates making museum displays more relevant to society's most marginalized groups but emphasizes the promotion of multiculturalism and tackling disaffection among young people, and is largely silent on meaningfully engaging with disabled people and people with intellectual impairment. Government policy on learning disability (Valuing People 2001) does not even mention the importance of cultural representation and imagery. Narrowly defined policy guidelines about inclusion of people with intellectual impairment in museum practice address intellectual access but very little else (DCMS 2001). In addressing social inclusion, museums have, not surprisingly, tended to follow government guidelines focusing on ethnic minorities, while disabled people and sexual minorities have been neglected (Sandell 2007b: 24).

The discourse associated with the new museological literature and social inclusion agenda suggests it is timely and appropriate for museums to be addressing learning disability in their collections and displays. In practice however most museums do not link social inclusion to impairment, even though people with intellectual impairment are amongst the most socially excluded and vulnerable groups in Britain today (Department of Health 2001: 21). In reality if museums are to be socially inclusive and if they are to present sensitive material on the history of learning disability, appropriate national museum policy needs to address this issue.

National legislation and policy on disability and representation

Taken together the Disability Discrimination Act, the findings reported in *Buried in the Footnotes*, the RCMG survey of disabled people in Colchester, and the disability policy guidelines produced by the MLA³ and DCMS all provide the policy context for the material representation of learning disability. Section 49A of the 2005 Disability Discrimination Act places new duties on public authorities, including museums, to eliminate discrimination against disabled people, to improve equality of opportunity for disabled people, to promote positive attitudes towards disabled people and to encourage participation by disabled people in public life. Thus providing access and amenities for people with intellectual impairments is not enough – fostering a wider understanding of disability is also called for.

The research that culminated in the publication of *Buried in the Footnotes* in 2004 was undertaken by the RCMG and is the first to make a connection between museums and their collections and the representation of disabled people. The study investigated material within UK museum and gallery collections that relates to the lives of disabled people, both historical and contemporary, conducting in-depth interviews at ten museums after an initial postal survey. In

spite of seventy nine per cent of respondents stating they had no or only one or two objects which were disability related, further exploration revealed that there was more material in the collections than previously acknowledged, curators often being unaware of their existence or the link to disability (RCMG 2004: 10). The main findings of this research were that although there was no evidence of curatorial attempts to suppress disabled people's history in museums, respondents often expressed anxiety and concern about displaying and interpreting material which resulted in inertia (RCMG 2004, 5). The main reasons given for museums' lack of engagement with issues of disability, was chiefly because of: '...fear of offence, making mistakes, transgressing unknown codes' (RCMG 2004: 10).

The Report concluded that the displayed material was limited in quantity and range and tended to confirm the stereotypical roles of disabled people in society (RCMG 2004: 12). Sandell (2007a: 171) confirmed that while some practitioners were enthusiastic about the idea of developing museum displays to offer alternative non-prejudiced ways of exploring and valuing cultural differences, others showed resistance to the notion of museums as agents of social change proposed by government (DCMS 2001).

Colchester Museums service commissioned the RCMG to undertake research that would determine the part museums can play in the representation of disabled people in the past and today (Delin *et al.* 2006: 10). The study aimed to generate a greater understanding in the museum service of how disabled people saw themselves, their heritage and their history and how they should be represented (Delin *et al.* 2006: 11).

Consultees' responses were diverse and cautionary. Young disabled consultees showed some incredulity at the ability of the museum to counter the years of silence on disability. One young disabled respondent said:

It would take millions of artefacts to show people that there are disabilities out there and to stop abusing it (Delin *et al.* 2006: 76).

They also felt that recognition of disabled people and their history and the provision of role models would encourage greater pride and validate their existence (Delin *et al.* 2006: 14-15). Colchester's own disability advisory group, Portal, felt that disability was not addressed by museums because curators and the general public were uncomfortable with disability (Delin *et al.* 2006: 61).

This ground breaking Report appears to be the first to directly consult disabled people to find out how they want to be represented in museums. What is disappointing though is the lack of references to people with intellectual impairment. The Report's extensive bibliography does not mention the work of the British Institute for Learning Disability (BILD) that has conducted extensive interviews with people with intellectual impairments to record their histories and life stories. Brief reference is made to the work of the Intellectual Access Trust, but this does not extend to cultural and representational access. Although not made explicit, it appears that no participants with intellectual impairments took part in the survey. The report (Delin *et al.* 2006: 47) states that because people with intellectual impairment rely heavily on support services and structures they will have less ability or find it inappropriate to participate in discussion led research and may be prone to be institutionalized and give conditioned responses that they feel museums wish to hear. It maintains that parents and other non-disabled gatekeepers may wish to 'talk' for such groups making intellectually impaired people particularly difficult to consult.

The MLA's Disability Survey (Bell *et al.* 2005: 1) aimed to discover the extent to which disability access has become an integral part of museum practice. The Survey (Bell *et al.* 2005: 4-5) found that 59% of respondents were aware of the 2005 DDA amendments, 99% felt that disabled people have the right to the same quality of service and 82% felt that disability should be represented in the collections of museums, libraries and archives. The Survey (2005, 11 and 17) did find, however, that consultation with disabled people and information available for intellectually impaired people was at a relatively low level. Twenty per cent of respondents stated that disability culture and disabled people were represented and that eleven per cent of display material originates from disabled people (2005: 18). Significantly survey respondents (2005, 18 and 22) flagged up inadequate guidance and information on intellectual access and the need to develop disability representation so that collections are more relevant to their communities as important areas for future development.

All the above reports suggest that intellectual impairment is still a significantly neglected area of museum policy. The MLA has produced checklists (2003) and toolkits (2004) advising museums on the issue, but there are no guidelines on how to meaningfully consult people with intellectual impairment or use historical material appropriately. What has also emerged is that curatorial anxieties explain in part why many museums avoid presenting material on learning disability.

Curatorial attitudes to learning disability: three case-studies

The findings of *Buried in the Footnotes* and the lack of national guidance on how to address learning disability in museums provide the backdrop to my own research⁴ which aimed to find out how curators viewed the issue. Three case studies chosen for comparative purposes were:

- 1 Colchester Museums Service considered by RCMG (Jocelyn Dodd pers.comm. 2007) to be very pro-active in ensuring the inclusive representation of disability in museum practice.
- 2 Thackray Medical Museum in Leeds because of its physical and historical associations with people with learning impairments.
- 3 York (Castle) Museum because it has never actively set out to represent disability generally or learning disability specifically in its exhibitions.

The interviews aimed to establish how much impact the Disability Discrimination Act, the new museology discourses and social inclusion agenda had had on curatorial practice. Staff were interviewed to find out if they had concerns about working with learning disability material mirroring those recorded in *Buried in the Footnotes*, or if they were receptive to the idea of displaying material relating to the history of learning disability.

The Castle Museum, one of four museums managed by the York Museums Trust (YMT) opened in 1938, and is described as one of Britain's leading museums of everyday life (Castle Museum website⁵). Best known for its recreated Victorian Street, Kirkgate and named after its founder John L. Kirk, Castle Museum is predominantly traditional, with glass cabinets displaying historic toys, weapons, fashion, ceramics and household items with some temporary exhibitions using more contemporary material.

When senior employees were asked how the Trust addressed the DDA, most talked solely about physical access, and work on intellectual access and consultations with disabled people had been limited to date. Opinions differed about whether the social inclusion agenda was having an impact on their work. Others felt that the social inclusion agenda was unhelpful as it targeted ethnic minorities. No one associated social inclusion with disability and two were cautious about addressing social inequality, one stating:

We try and be neutral. We have not really developed a community approach yet where community voices are heard. Hopefully that will change.

There was no material on learning disability known to be at the Museum. With two million artefacts in its collection and only five per cent catalogued, some unknown material may of course exist. There is a wealth of material relating to learning disability at the Borthwick Institute in York and the North Yorkshire County Records Office. The former holds material relating to disability dating back to medieval times and include early patient records from York's asylums and mental deficiency hospitals that particularly show the impact of the 1913 Mental Deficiency Act on the lives of people with intellectual impairment and their families in York.

In spite of an acknowledgement that learning disability is significant to York, home of the once famous York Retreat asylum, the Museum has neither collected nor displayed material on learning disability. One senior curator observed that 'ensuring that disabled people are in the collection and displays as part of the general population is not on my horizon yet'. Another maintained that:

York has a strong history of learning disability with its connection to the York Retreat. I don't think a lot has been done on representing that area in this museum. The work here is collections driven.

References to neutrality and a comment that some interpretative panels had not changed for twenty years revealed a traditional approach that permeated the collection and displays. Little progress had been made on including people with learning impairments in museum policy. The lack of displayed material on disability, however, appears to be the result of some underlying anxieties and inertia rather than open hostility or lack of interest in the subject matter. A mood, revealing a felt need to change, was evident from interviews, which might impact in greater outreach work and consultations with disabled people, the development of new partnerships with organizations such as the Borthwick and displays on learning disability in the future.



Female Inmates, Leeds Union Workhouse, late 19th century (photo courtesy of St. James's Hospital)

Thackray Museum, the second case study, is housed in the former Leeds Union workhouse and is part of St James Hospital that used to accommodate people with intellectual impairments. Opened in 1997, its initial focus was on the medical supply trade but this has widened to include public health and medical social history. The collection consists of over 35,000 historical and contemporary objects and includes a large number of artefacts relating to disability including artificial limbs, and a sixteenth century orthopaedic correction frame. A temporary outsourced exhibition about DNA and genetic disorders included material relating to people with intellectual impairments. The only permanent learning disability material displayed included a small exhibition on the history of the workhouse that included the photograph of female 'inmates' (see fig). Staff showed interest in finding more information on the history of the workhouse and infirmary complex. The collection did have, in store, a range of material relating to learning disability in the store that comprised a Downs Syndrome testing kit and several intelligence testing kits used by educational psychologists. There was, however, not a lot of interest in displaying the learning disability diagnostic material. To display such material would reveal former medical practices that had stigmatized intellectually impaired people as 'other', and helped remove them from society and, as such, would be a departure for a medical museum whose main purpose is to show the scientific development of medicine and the positive contributions medicine has made to society.

The Disability Discrimination Act has had an impact on museum practice. Thackray Museum's Access Strategy 2006 – 2009 includes a SWOT analysis of the Museum's strategic position in relation to access. It identifies among its strengths a commitment to build access into

its core objectives, staff commitment to access and a high level of access throughout the Museum (2006: 1.3). The document also recognizes the lack of consistent consultation with disabled audiences and inconsistent access awareness among staff. The SWOT analysis also identified the increasing professional and public interest in access to and interpretation of the 'hidden histories' of disability as an opportunity (2006: 1.3)

The Access Strategy is broad in its scope and sets out its commitment to tackling organizational, sensory, intellectual, social/cultural, financial as well as physical barriers to access (2006: 2.2). The Museum is exploring ways to offer different opportunities for learning for people with different learning styles -following the VAK [visual, auditory and kinaesthetic] model and that advocated by Kolb (*Access Strategy* 2006: appendix 1).

The Museum's commitment to social inclusion included consulting people with a variety of impairments. Equating social inclusion with access is unusual in museum practice (Kawashima 2006), particularly as the DCMS (2001) do not provide clear guidelines to do so. Consultations with visually impaired people, for example, were being undertaken to produce a new audio guide tour of the Museum. The Museum is exploring the possibility of a similar tour aimed at improving accessibility for people with learning difficulties, and for those whose first language is not English.

A very positive attitude to representing disability emerged and was typified by these curatorial comments:

Museums are for every part of society. The Disability Discrimination Act encourages the portrayal of people with disabilities in its guidelines for museums. We are encouraged to do this. Disabled people are marginalized unfairly. Museums are encouraged to use the social, rather than the medical model of disability, which encourages the incorporation of people with disabilities, more fully into society.

What distinguishes Thackray Museum from the Castle Museum is its willingness to develop new opportunities that are not collections based. The temporary exhibition *Molecules for Life* on genetic disorders is based predominantly on material from the charity Jeans for Genes that raises funds for genetic disorders. Like York's Castle Museum, Thackray Museum has not catalogued everything and so it may hold unidentified material relating to learning disability. Thackray's curatorial staff showed significant awareness of the issue of intellectual impairment and a strong commitment to addressing intellectual access in their displays. Connections between social inclusion, audience development and access strategies were made which is rare in museum practice (Dodd and Sandell [2001] and Sandell [2007a]).

Colchester Museum Service, the third case-study, has four museums of which Hollytrees Museum is the most relevant given that it displays three hundred years of Colchester's social history. Colchester has a forward thinking approach to representing material relating to disability. One of the first museums services to establish a disability advisory group, they have run several conferences on disability and commissioned research on the subject [Pearson (2005) and Delin *et al.* (2006)].

Colchester adopts a comprehensive and varied approach to disability which touches every aspect of the museum service. The perspective of one curator that 'disabled people are part of everyday life –and therefore the museum needs to represent them along with everyone else' is echoed in the way that disability material is presented. Although, according to one curator, Colchester does not have a terribly rich collection, several items relate to disability. The material comprises: institutional history, walking aids, medical equipment, photographs and artwork of disabled people and a significant oral history collection of three thousand interviews called *Colchester Recalled*. Material relating to learning disability includes bathing regulations, information about meal times from Severalls mental health hospital, and a photograph of Essex Hall, County asylum.

Hollytrees Museum has been praised by RCMG for sprinkling stories about disabilities throughout. A montage of contemporary and historical figures from Colchester for example includes postcards of two sisters called *The Silly Anna's*, dressed up as a princess and a handmaiden, and works by John Vine, a nineteenth-century disabled artist, who was of diminutive stature and had undeveloped arms and hands

Colchester Museum's service appointed Jane Pearson, to research their collection and to locate other local resources on disability. Her report confirmed the presence of stored disability items, but, in common with Thackray and YMT, found that the museum's database was inadequate to make best use of these accessions (Pearson 2005: 4,12). From the archaeology and excavations databases it was impossible to tell if several potential artefacts such as a post medieval shackle and feeding bottles, for example, were associated with disability (Pearson 2005: 14).

In spite of Colchester's pro-active approach to disability, it was acknowledged by my interviewees that when it came to consulting people with intellectual impairment for their Heritage Lottery Fund (HLF) sponsored exhibition *Life Beyond the Label* this was not easy:

I think it is the toughest area museums have to deal with. There is hesitancy about working with such groups – partly out of ignorance of how to work with them. Exhibiting material generated by projects working with people with learning difficulties is far easier as you are employing other agencies who are specialists at working with people with learning difficulties.

Colchester has undertaken a considerable amount of outreach work with the local Gateway Group which has resulted in a number of conservation, arts and theatre projects. The *Life Beyond the Label* exhibition however was breaking new ground. One curator explained that the exhibition aimed to: 'try to dispel the stereotypes associated with the label of disability and to look at the people behind the tag'.

The MLA's Disability Survey (2005: 18) found that nationally only eleven per cent of museums' material relating to disability originated from disabled people. For *Life Beyond the Label*, Colchester staff collected material originating from disabled people and their families, to enrich the collection with testimonies and human interest stories. A *Disability Roadshow* generated new material for the forthcoming exhibition, including aids and equipment specially designed for children with a range of impairments, with their associated stories, and a photograph album given by the wife of a local man, Morris Hall, who had spent most of his life in a spinal carriage.

Unlike many traditional museums that are solely focused on using their existing collection, Colchester Museums Service, like Thackray, are developing exhibitions on disability even though the material they need is not necessarily available from their collection. Colchester is also one of the few museum services to work with Social Services who coordinate oral reminiscence work with adults with learning impairments, replicating 'best practice' advocated by Marwick (1995), Mackechnie (2001) and Kavanagh (2002). Engaging with people with intellectual impairments was not without its problems. Curators were anxious about the issue of permissions from people with learning impairments, whose openness created concerns that the sensitivity of the material may offend their carers or families. Because there were no precedents, staff were unsure whether participants understood what they were being asked to give permission for, and obtained advice from Mencap⁷. (Mencap produce a downloadable factsheet which explains the Mental Capacity Act 2005 which explains appropriate procedures to be used to obtain consent from people with learning impairments and has useful tips about appropriate communication methods).

One interviewee suggested that more advice on how to tackle the issue of learning disability was needed as 'a lot of museums are nervous about it. I'm not aware of particular advice from the MLA or other national organizations on this. Learning disability has been sidelined a bit'.

The three case studies and the findings of *Buried in the Footnotes* have established that curatorial anxieties exist about presenting material on learning disability. The obstacles and opportunities facing museums wanting to present such material are now explored in more detail.

Presenting material on learning disability: a way forward

Shakespeare (2000) is one of the few to write specifically about the cultural representation of people with learning impairments. Shakespeare argues that historical records relating to people with learning disabilities are nearly always medical 'case histories' that contain clinical

information of value to the professional, rather than personal histories or family details (Shakespeare 2000: 12).

Some archives contain biased, usually medical, perspectives but not all do. The Borthwick Institute, for example, contains a wealth of information about Yorkshire's former learning disability institutions including Victorian photographs of patients, family history details, case notes and visitor books. Historical archives inevitably include insensitive language associated with intellectually impaired people but used appropriately can highlight historical prejudices and be countered by positive life affirming statements by people with learning impairments (see Bristol Museum's work below). Museums can supplement archival information with a life history approach, while art and theatre work can be used to facilitate discussion and effectively engage people with intellectual impairments. Partnering agencies such as Social Services to facilitate consultation processes has also worked well (Mackechnie 2001).

Intellectually impaired people have been subject to persistent discriminatory practices by social and political as well as cultural institutions. Persistently avoiding consultations with intellectually impaired people because of its challenging nature is still discrimination. There are numerous avenues for accessing the views of intellectually impaired people. Several advocacy groups such as People First, Social Services departments, hospital trusts and Mencap have all worked with museums. For *Buried in the Footnotes*, the RCMG interviewed various disabled spokespersons and yet did not attempt to involve anyone from People First or writers with intellectual impairments such as Simone Aspis. Aspis has written about her interest in learning disability research and her frustration at not being taken seriously by, or included in work undertaken by, research institutions (Aspis 2000: 1-5). Goodley and Armstrong's study of self advocacy (2001) also referred to the absence of people with 'learning difficulties' in disability studies and ironically the RCMG has failed too in this respect (see reference to RCMG, Delin *et al.* 2006 above).

Oral history interviews if tackled sensitively can provide a unique and in depth insight into past lives. It is a particularly important currency of communication for former patients of institutions; and can be liberating and life changing, enabling museums to bear witness to 'the best and the worst, the extraordinary and the mundane, the innovative and the traditional' (Kavanagh 2002: 120). BILD has produced numerous publications on using oral history approaches to explore the history of learning disability (e.g. Atkinson *et al.* (2003); Potts (2000) and Rolph (2000) *etc.*). Oral history approaches, however are not without problems. Ure (2005) found that many people with learning impairments that she interviewed had no sense of historical time. Although most people with mild and moderate learning impairments have developed an understanding of the past, some may have language (and therefore grammatical) difficulties conveying this (Uden, pers. comm. 19/06/08). Thus adequate preparation and a realistic time scale are important in order to gain some insight into preferred methods of communication and interaction at the outset (Uden pers. comm⁸. 19/06/08; Rolph 1998).

The following learning disability projects and exhibitions illustrate how some of these challenges have been overcome and provide examples of best practice that can be emulated elsewhere.

Best practice

Nationally there are very few examples of good practice where museums are presenting material that reflects the histories and lives of people with intellectual impairment. A selection of the few that do exist are summarized here and reflect the importance of oral history and consulting people with intellectual impairment to overcome the lack of material evidence in traditional collections.

The HLF is keen to fund more heritage projects that specifically set out to meet the needs of people with learning difficulties (Crosby personal comm. 2008). Access and disability policy officer to the HLF, Tony Crosby, confirmed that museums that apply for funding, take their responsibilities under the Disability Discrimination Act seriously, but are not always aware of how they can meet the needs of people with intellectual impairment (Crosby 2005: 16). Oral history and archive projects exploring the social history of disabled people are increasing, exemplified by the *Reclaiming the Past* project in East Anglia where six Mencap societies collated material on the history of post war community care for people with learning impairments (Crosby 2005: 17).

A small HLF grant was given recently to record the history of Northern Ireland's Muckamore Abbey Hospital for people with intellectual impairment from 1948 to 2000. Considered to be a significant part of the area's medical and social heritage, former patients and medical and nursing staff provided reminiscences, photographs and documents which along with archive sources culminated in a book, *A History of Muckamore Abbey*. Led by volunteers, the project explored the changing social attitudes towards and experiences of people with learning disabilities and their carers and appears to be the only learning disability hospital whose history has been grant aided by the HLF as a 'heritage project'. Although museum services were not involved, the potential to replicate such a project and present such historical material in exhibition format are obvious.

The Museum of London's Disability Equality Scheme aims to ensure they include disabled people fully in the life of the museum. They have undertaken a collections audit to reassess what they collect and have undertaken art, video and filmmaking projects with disabled groups to record what London means to them. Their collections include important material relating to intellectually impaired people including information about the Eugenics Society. They have launched a website *Exploring 20th Century London* which explores issues of disability and disabled people's struggle for equality (MOLG 2007: 3). One of their projects *London Inside Out* provided outreach sessions to 11,500 children in special and hospital schools throughout London, many of whom were previously unable to visit the museum due to physical or learning impairments (MOLG 2007: 3).

What sets the Museum of London apart is its mission to develop the Museum Group's reputation as leaders in equality and diversity (MOLG 2007: 6). The museum aims to establish a Disability Access Group and is liaising with Colchester Museum Services to learn about the successful establishment of their access advisory group PORTAL. The museum has set out a Disability Action Plan in which it details its commitment to recruit disabled people in the development and recording of collections.

Museums that specifically display material relating to learning disability history are rare. An exception was an exhibition entitled *The Journey to Inclusion* developed in 2007 by Bristol's City Museum and Art Gallery in conjunction with the Learning Disability History Group attached to Bristol and South Gloucester's People First organization. The group recorded the life stories of staff and patients at long stay mental deficiency hospitals in the Bristol area. With the aid of support workers, the group developed an interactive time line which showed changes in learning disability policy from the founding of Bedlam to the present day. People First also explored the barriers many people with learning difficulties have experienced in their lives and included quotes about personal accounts of discrimination along the time line. Using mixed media including photography, audio and video clips, inspired by Harry Potter films, the participants, aimed to change people's attitudes towards intellectually impaired people.⁹

In 2006 the HLF granted £360,000 to the project *Rethinking Disability Representation in Museums and Galleries* which grew out of *Buried in the Footnotes* (Sandell 2007a). Nine museums and galleries, including Colchester Museums Service participated in the project which aimed to rethink approaches to display and interpretation of collections linked to the lives of disabled people and the history of disability. The project sought to challenge prejudice and contest reductive stereotypes, address the 'difficult stories' surrounding disability history, and present the diversity of disability experience, and thus contribute towards a more inclusive national heritage (HLF website¹⁰). Welcoming the project, actor and author of *Thalidomide! A Musical*, Mat Fraser said:

It's scandalously overdue but I welcome any initiative that finally allows us out of the shadows of segregation and into the light, and I look forward to celebrat(ing) our full inclusion in the museums of Britain. Our stories are fascinating and add to the rich cultural tapestry of our own history, something that all museum visitors should be able to enjoy (HLF website¹¹)

Wider Implications and conclusions

The three case-studies and examples of best practice offer a number of models for other museums to emulate. Successful partnerships with agencies such as Social Services and

Mencap and an open and sensitive approach to engaging with disabled people in Colchester and elsewhere appeared to dispel initial anxieties and to build sustainable working practices. My research however revealed key areas that need to be addressed if more museums are to represent material on learning disability. Relatively few of my interviewees exhibited confidence and knowledge about the issue of learning disability. Most regarded the issue as difficult, challenging, sensitive, an unknown and were unsure how to address it or where to find advice on the subject.

Assumptions that intellectually impaired people cannot speak for themselves, highlighted by Shakespeare (2000) and Delin *et al.* (2006), deter museums wanting to represent their lives and histories. The views of organizations such as People First, INTACT, BILD, Mencap and Gateway, and proponents of advocacy for intellectually impaired people such as Goodley and Armstrong (2001) could be sought, to establish how people with intellectual impairment can best be consulted about their social history and how this can be culturally presented.

Whereas consulting disabled people generally is not problematic, undertaking meaningful consultations with intellectually impaired people is more challenging, requiring a greater lead in time and external support to establish reciprocally beneficial means of communication. Although the learning styles and preferred communication methods vary significantly among people with mild and moderate learning impairments there is, arguably, still scope to provide generic guidance on how to effectively engage with and present cultural material about people with intellectual impairment.

The only examples I found of museums attempting to produce exhibitions on learning disability history were Bristol and Colchester Museums service. Today there is a quantitative and qualitative lack of material in museum collections relating to the history of learning disability and a dearth of museological literature on the subject. Yet ample historical accounts exist that explain why and how intellectually impaired people's place in society has changed over time and these can and have been enhanced by oral testimonies.

However, the danger that the history of learning disability will be forgotten is a real one if records of former educational and medical institutions that accommodated people with intellectual impairment are discarded. Learning disability forms a fundamental part of our social and medical history that museums are currently inadvertently or deliberately ignoring. Museums that profess to be socially inclusive and open to multi-vocality have an important role to play in preserving this cultural legacy by ensuring such histories are represented in their collections and displays for the enlightenment of existing and future generations

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Notes

- ¹ DCMS, the Department of Culture, Media and Sport, is the UK central government department which, amongst other things, sponsors museums and galleries in England.
- ² RCMG, or the Research Centre for Museum and Galleries is located at the University of Leicester.
- ³ MLA or the Museums, Libraries and Archives Council is a strategic national agency which is charged with promoting best practice in museums, libraries and archives. It was established in 2000 under the sponsorship of DCMS and replaced both the Museums and Galleries Commission (MGC) and the Library and Information Commission (LIC).
- ⁴ This article is based on findings of research undertaken for a dissertation as part of my MA in Archaeological Heritage Management at the University of York in 2007. The research's key aim was to establish curatorial attitudes to including material on the history of learning disability in museum collections and displays and to generate greater understanding of the challenges and opportunities museums face if they decide to present such material.

Senior management and curatorial staff were interviewed in three case-study museums - Colchester Museum, Thackray Medical Museum and York's Castle Museum. Exhibitions were visited and where the opportunity arose, non displayed catalogued material searched prior to interviews to find out if the quality and extent or lack of information had a bearing on attitudes. Internet, telephone and literature searches were also carried out to illustrate the methodological approaches used by museums elsewhere to presenting material on learning disability history.

Time constraints prohibited interviewing people with learning impairments or their carers/advocates to assess their views on the use of material on learning disability history in museums – something which would have provided an insight into issues such as sensitivity and determining what is 'appropriate' and meaningful to those whose lives are being depicted. Without this perspective it is difficult to avoid adopting a 'professional/academic' view about what is 'best practice' and conclusions about 'successful' approaches to addressing this issue.

- 5 Castle Museum website consulted 24/07/07: <http://www.yorkcastlemuseum.org.uk/Page/YorkCastleMuseum.aspx>.
- 6 All comments made by interviewees were made in confidence and therefore remain anonymous.
- 7 Mencap is a major British charity which works with and on behalf of people with learning disabilities.
- 8 I am grateful to Monica Uden, head of Forest School, Knaresborough for sharing her experience and specialist knowledge in communication difficulties in people with autism and learning impairments.
- 9 Jackie Winchester, Museum Learning Officer , Bristol Museums service, pers. comm. 30/07/07.
- 10 HLF website consulted 22/08/07 <http://www.hlf.org.uk/English/MediaCentre/Archive/Representing+disability.htm>.
- 11 HLF website consulted 22/08/07 <http://www.hlf.org.uk/English/MediaCentre/Archive/Representing+disability.htm>

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***Kathy Allday** initially pursued a career in town planning, developing a particular interest in disability and community consultation work. She established the charity Bradford Shopmobility and has campaigned regularly for better facilities for people with intellectual impairments. She began studying archaeology at the University of Leeds in 2000 and set up the Leeds Archaeological Fieldwork Society in 2005. The Society is currently undertaking an excavation in East Leeds. She has recently completed her MA in Archaeological Heritage Management at the University of York and hopes to further her research on the history of learning disability and its representation in museums.

E-mail: kmallday@fsmail.net