Our Disabled Bodies Ourselves:
Restoring Humanity Through Archival Description

Abstract:
This capstone focuses on memory and memorialization, particularly as it relates to archival practices around human remains of the disabled. Skeletons and mummified remains of nearly 30,000 people dwell in the vaults of the Smithsonian Institution. Museums around the world have large collections of human remains as well. Most of these bodies were collected with very little cataloging data which further removes them from their humanity. The bodies of women and men who were loved by their families and might have been honored by them in death became mere objects for study. Bone rooms are “the worst legacies of colonial anthropology in the nineteenth and early twentieth centuries.” (Redman, 2016) I am keenly fascinated by how storing these entities relates to major power imbalances such as personhood. When these bodies lack appropriate description, they become natally alienated and ahistorical so it is easy for institutions to project meaning on them. This ties into the larger concept of the “displacement of cultural heritage

Keywords: Bone Rooms, Medical Archives, Disability, Medical Model of Disability, Human Remains, Metadata, and Archival Description

Statement of the problem:

The disabled are the largest minority group in the country yet they are largely ignored in archives (Brilmyer, 2021). During the process of arrangement and description, a disabled identity is formed. The bodies of the disabled have been used in archives and collections to further ideas related to eugenics; this practice continues today. The entities in many of these collections lack permissions, even ones that were collected as recently as 1985 (Levenson, 2021). This capstone will examine the portrayal of disability in the metadata in medical anomaly archives.The goal of this research is to determine how the language used in archival description can restore humanity to the dead stored in archives.

The bodies in medical anomaly archives can serve as educational tools to teach visitors about human anatomy and illness (Sofaer, 2006). These bodies can also be used to further other the disabled and turn them into historical objects for study. The language used in the metadata is powerful and plays a vital role in framing these entities and the disabled community as a whole. Medical anomaly archives are concerned with the unusual but this focus on the curious can turn the archived dead into “freaks to study”. This ties into larger narratives of showmanship and freak shows (Redman, 2016). Many of these entities were collected during the freakshow era and their description and metadata bares the scars of their problematic past (Redman, 2016). This study endeavors to examine if this problematic language of the past still exists in the metadata in archives and if disability plays a role in archival description.

Purpose of this Study:

The purpose of this study is to examine metadata practices used in medical anatomy archives for human remains. It will place metadata into the larger narratives of how disability is viewed in society historically. Consent and bodily autonomy in relation to archives will be explored as well. Narrative construction in archives through metadata will be thoroughly examined and unpacked. Most concretely this study will explain what humanity restoring metadata looks like and what the future of metadata in medical anatomy archives should look like.

Scope and Focus of the Study:

The scope of this research is the use of metadata in medical anomaly archives. To conduct this research a group of four representative monographs published by medical anomaly archives will be studied as a means to understand larger trends in archival description in relation to disability. These texts were chosen from a limited group. Medical anomaly archives don’t frequently publish monographs of their collections so there were limited options for texts to study.

Description of Research Methodology:

This study will be a content analysis of four monographs published by medical anomaly archives of their collections. The most recent monographs from each museum will be studied. There has not been a content analysis of metadata present in this type of monograph before. Reviews of these books in the past have been cursory and not about the use of language as their message had to be approved by the institutions before publication. Content analysis allows unfettered access to information without compromising the integrity of the materials. This research will examine an established form of collection promotion to see larger patterns in disability portrayal in archives.

Justification:

The monographs being analyzed are descriptive in nature which is best studied through content analysis. Content analysis is known as a reliable method of study for the following reasons: stable intercoder reliability, results are theoretically reproducible, and accurate. Content analysis is an unobtrusive research method which is especially important when working with materials from historically marginalized communities. Leaving no trace was especially vital to this research to avoid enacting continued violence against the disabled. A survey where archivists from each collection were asked about language usage would have been difficult because it would allow for respondent biases in a much larger way. A case study would have been too time consuming for the amount of time that was given for this study.

Research Design:

A coding scheme was developed based on the criteria discussed in Brilmyer (2018, 2021, & 2022), Redman (2016), and Stanton (2021). The Stanford Disability Language Guide forms the basis of the criteria on metadata language uses. The investigative thrust of this project is the use of language in metadata and its relationship to disability portrayal. This is an analysis of if language used in metadata shows traces of the portrayal of disability. Language is vital to this research so the coding scheme needs to be focused on linguistics.

Research Design:

The sample texts for this study were chosen from a limited group. The texts needed to be originally written in English because of the importance of language to this study. There was too much risk in using translated text because translation is not an exact science (Pym, 2004). This study relied on monographs written by museum staff that conformed to metadata policies for each archive. These books had limited text runs with many monographs never put into library collections so it was a struggle to find needed texts. The final group of books are from North America, France and a traveling exhibit that originated in Germany but have now been shown around the world.

Data Processing, Coding, and Analysis:

Each monograph was read twice for accuracy within the coding scheme. The overall goal of this study is to examine disability representation in archives. The question of if/ how disability is described within archival metadata schemes is the thrust of this research. Notes were taken during the first reading based on general impression. The second reading responds to the coding scheme shown above.

To process the data that was recorded, the number of instances when each text matched the coding scheme was notated. After each instance was finalized, it was then analyzed to make sure it responded to the research questions. Every analysis was then recorded in a chart. Once all of the data was organized, it was then interpreted, leading to conclusions about how the disabled are portrayed in archives.

Limitations:

The sample size for this study is limited which makes this research less generalizable. Two of the books that were needed for this research were impossible to buy and the New York Public Library lost all of their copies of the two texts which further shrunk the size of this study. Museum monographs are heavily edited before going to print and sometimes have sensitive readers so the metadata might not be fully reflected in the texts. The monographs were all written in the last two decades so they may in general follow contemporary ideas of disability. All of the books for this survey are from North America and Europe so they privilege a global “western narrative” around death and disability.

Preliminary Findings:

This is an analysis of three books that each correspond to a different archive/exhibit. The first, Gunther von Hagens’ Body Worlds; the Original Exhibition of Real Human Bodies
Humanity or Pathology (2009), is a catalog from the highly controversial exhibit Body Worlds (Walter, 2004). “The primary goal of [Body Worlds’] exhibition creators, Dr. Angelina Whalley and Dr. Gunther von Hagens, is preventive healthcare.” (Body Worlds, 2021.) The educational value of this exhibit has been brought into question and some see it as a modern “freak show” (Walter, 2004). The second book, A Descriptive Catalogue of the Warren Anatomical Museum (1870), is a list of all of the archival metadata from Harvard University’s medical archive. This text doesn’t have any images, but it provides a clear guide to Harvard’s language usage within their archive. The third and final text is Fragonard Museum: The Écorchés (2011) is a catalog of entities from eighteenth-century anatomist Honore Fragonard’s écorchés. These entities include both human and animal remains. This book also speaks to the history of medical collections that contain human remains.

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