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UNPACKING SOCIAL AND STRUCTURAL ROADBLOCKS TO ACCESSIBILITY IN SOUTHERN ILLINOIS UNIVERSITY CARBONDALE

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by

Abimbola Olamide Iyun

B.A., University of Ibadan, 2011

A Research Paper

Submitted in Partial Fulfilment of the Requirements for the

Master of Science

Department of Mass Communication and Media Arts

in the Graduate School

Southern Illinois University Carbondale

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RESEARCH PAPER APPROVAL

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Approved by:

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AN ABSTRACT OF THE RESEARCH PAPER OF

ABIMBOLA OLAMIDE IYUN, for the Master of Science degree in MASS
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TITLE: UNPACKING SOCIAL AND STRUCTUAL ROADBLOCKS TO
ACCESSIBILITY   IN SOUTHERN ILLINOIS UNIVERSITY CARBONDALE

MAJOR PROFESSOR: Dr. Lisa Brooten and Prof. Jay Needham

        This research paper alongside an audio documentary, Living In Our Space, explores

from the perspective of four students with physical disabilities at Southern Illinois University

(SIU) consistent issues of inaccessibility and its effects on students with disabilities at SIU. It

explores what inaccessibility means for participants in this study and how it affects their

lives. Data was gathered through the use of semi structured interviews and autobiographical

accounts and analysed with thematic analysis and In Vivo coding.

DEDICATION

To the all knowing and wise God, to you be all the glory!

ACKNOWLEDGMENTS

PREFACE

This research paper is coupled with an audio documentary, Living In Our Space, in order to explore how participants in this study describe inaccessibility and its effects on their lives. Participants share their accounts which are presented in the audio documentary and discussed as themes in this paper. A core essence of this is to enable us understand from the perspective of these participants the different forms inaccessibility presents itself and how it has affected their lives.

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CHAPTER 1

INTRODUCTION

Through an audio documentary and a research paper this project explores, from the

perspective of four students with physical disabilities at Southern Illinois University (SIU),

consistent issues of inaccessibility and its effects on students with disabilities at SIU.

Participants are students who are currently advocating for better accessibility at SIU and are

part of two student organizations, AccessAbility and Accessibility Coalition. They were

chosen using purposive sampling. They have been willing to talk about their experiences as

students at SIU and responded to the request to participate in the study. With the use of in

depth interviews and autobiographical accounts, this project is collaborative, as I work with

students with disabilities not just as interviewees but as participants who are kept up to date

and involved in the representation of their voices in the research paper and the audio

documentary.

History of SIU and Accessibility

Historically, SIU has been known to be a disability friendly environment. In an

interview with Sam Goodin, the director of Disability Support Services (DSS), he discusses

that SIU has been an institution known for its accommodations for students with disabilities.

Before the American with Disabilities Act was passed in 1990 Goodin says SIU was

accessible to ensure that veterans returning home could have a suitable place to study

(personal communication, October 14, 2015). In a 2013 annual report DSS details that it is

committed to working with students with disabilities to ensure that they have access to the

needed facilities to aid their academic pursuits at SIU (Southern Illinois University Disability

Support Services, 2013). Participants in this project have mentioned that DSS has been

instrumental in ensuring they get settled in classes and also speaking to professors about the needed class accommodations.

In order to have more understanding of SIU's commitment to disability services, Goodin also suggested I meet with Carol Lepere, a staff architect at the Physical Plant in SIU. In an interview, Lepere showed me stacks of surveys which SIU and Illinois Capital Development Board (CDB) had carried out through an architectural firm. The surveys, consisting of 12 volumes of booklets, were issued in 1994 and identified corrections that had to be made in 127 buildings and locations on campus. The survey was carried out to record corrections that had to be made in buildings and locations to meet American Disabilities Act (ADA) requirements. It also included a budget of the cost of making the corrections and details since 2005 the progress made in making the needed corrections in buildings at SIU. According to the notes sent to me by Lepere, $11,582,974.21 has been spent on carrying out corrections in buildings up to 2005. Lepere also emphasized that there are installations made in buildings which are not necessarily ADA requirements but installed by the administration to ensure the school was more accessible. One of those is the brail room numbers on doors in buildings for blind students to read. She also pointed out that the Physical Plant takes care of all repairs and maintenance on campus to meet ADA requirements (personal communication, October 20, 2015). From the interviews with Goodin and Lepere it is evident that SIU is committed to ensuring that the institution is accessible for students with disabilities. Also, participants in this project express that DSS has been instrumental to ensuring that they had a smooth transition into SIU. One of the possible reasons for current issues discussed by students in this project may be due to the current budget crisis at SIU which has limited the allocation of resources to addressing issues of inaccessibility in buildings.

Current Issues with Disability Services at SIU

As stated in the previous section SIU has been known to be a historically accessible institution. Discussions made in this project are aimed at raising awareness about current

issues in the institution so it can continue to maintain its standards. In recent years there have been complaints from students with disabilities about accessibility issues at SIU. Civic Soul, an organization that uses media to advocate for social issues in Southern Illinois and beyond, organized a forum for persons with disabilities at SIU in Spring 2015 where a majority of the concerns raised by students and non students with disabilities were on inaccessibility issues at SIU and in Carbondale. I followed up on this project because I was moved by the stories of inaccessibility and wanted to contribute to the process of raising awareness about the issue at SIU.

Following up on my interest, for a journalism class in Fall 2015, I filed a Freedom of Information Act (FOIA) request with the Associate Chancellor of Institutional Diversity on complaints filed by persons with disabilities. I checked with the Disability Support Services at SIU to also confirm if they receive or file any formal complaints from students with disabilities and found out that at the time I checked, they do not have a formal process to document complaints. The report from the Associate Chancellor of Institutional Diversity at SIU shows that 52 students, staff and persons with disabilities at SIU filed complaints from 2010-2015. Some of the complaints pertain to faculty's attitudes towards students with disabilities, while others involve accessibility issues on campus. Accessibility here may include the availability of facilities such as power operated doors, sidewalks, elevators and housing that enable students with disabilities to live independently. Independent living involves the ability of persons with disabilities to live with the support of needed facilities as individuals in the society. The discussion from the forum and the report from the Associate Chancellor of Institutional Diversity sparked my interest in inaccessibility issues at SIU and in Carbondale. As a student at SIU, I was oblivious to the inaccessibility issues on campus, especially since SIU has a history of being an accessible campus.

From subsequent meetings and interviews with the disability community through Civic Soul, I gathered that there continue to be accessibility issues at SIU and in Carbondale that some students with disabilities want to address. In the past year, these students have been carrying out their advocacy independently and have not been able to realize their goals in terms of better accessibility. This project brings their requests for better accessibility together by connecting accounts of their lives as students and their advocacy work in an audio documentary and research paper aimed at raising more awareness about accessibility issues at SIU.

Through autobiographical accounts detailing experiences of project participants at SIU and in Carbondale, and through in-depth interviewing exploring how they speak about themselves, their advocacy work and their disability, this project explores participants' experiences of inaccessibility and how it affects their lives.

The relevance of exploring social perceptions on disabilities

Some persons with physical and mental disabilities have said that they believe people in the society consider their disability to be a burden. The sense of being a burden may emanate from the reaction some persons with disabilities receive in their interactions with other people. Nika[1], a blind student at SIU and a participant in this project, recently told me that on occasions when she uses her cane, she feels people ignore or stare at her. Specifically, on visits to restaurants, the waiter or waitress would direction questions to her partner. She explains that she perceives that people deem her as incapable of reasoning and that feeling tends to push her to withdraw from society. She says, "We can live independently but the society disables us" (Nika, personal communication, February 29, 2016). The social reaction to persons with physical or mental disabilities can be disabling. By ignoring the social discourse of persons who identify as having a disability, people can present themselves and

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[1] Nika and the names used for the other participants are pseudonyms used for the purpose of anonymity

society as inaccessible. Society here includes able bodied persons, institutions and power structures that may exert some influence over persons with disabilities. One of the major things that can influence people's perceptions and reactions to persons with disabilities is their understanding of disability.

Defining "Disability": Medical Discourse versus Critical Disability Discourse

Disability is broad in meaning. It is important to explore attempts made to define and explore disability in order to establish how definitions represent perceptions about disability. Also these explorations are relevant to reiterate the need for persons with disabilities to speak for themselves about their identity and in order to interrogate how they are identified by others. This is because there is a possibility that how others speak about disability may create assumptions about disability that are forced on persons with disabilities as a form of identity.

For instance, the medical field describes the bodies of persons with disabilities as a problem that needs to be fixed (Turner, 2009). It compares the bodies of persons with disabilities to those of the able bodied and treats and regards persons with disabilities only within the confines of their physical body (Turner, 2009). In essence it presents two sides, the one side which is the able body that is "normal", normal being the standard of what every physical body should look like, and the other side is the body of a person with a disability that is abnormal because it is different from the able body. I recognize that there are differences in the ways the bodies of people with physical disabilities are structured, however this kind of analysis has the tendency to ignore every other thing the person is in terms of their personality, talents and more. When people focus on the physical body alone it limits the perception of what people think the person is and what they can achieve. The perception also places persons with a disability on the margins of society where because of their difference they sometimes feel they are not part of society. Sandahl and Auslander (2005) discuss how "unlike the social-construction and minority models of disability that emphasize

group cultural identity, the medical model individualizes disabled people by considering them unique, unfortunate victims of pathologies, rather than a group of citizens deserving of civil rights" (p.129). As Sandahl and Auslander (2005) explain, the perception that persons with disabilities are only identified by their physical body can marginalize, thereby restricting them from living as part of the larger population. This shows in the way our environment is physically structured. Some students with disabilities discuss how the physical structures in their everyday lives make them feel they are not a part of society. Persons with disabilities regularly construct and speak about their identity by engaging with social discourse on disability and the understanding of inaccessibility.

Discourse on disability by persons with disability is relevant to challenge the comparison by the medical discourse of the disabled body with the able body. Anything contrary to the able body is often represented as a "dis-ability" which generally has negative connotations, such as those with disabilities being unable, slow, not meeting the standard of ability, and this discourse can and is dominating the discourse defining disability. Persons with disabilities are speaking for themselves about their identities, opening up more conversations on what disability is and reinforcing that it is not one single identity. This challenges the perception that the disabled body is not "normal" because it is different from the able body.

Critical disability discourse challenges that of the medical field. Scholars in this field have argued that disability should not be categorised or defined as one single identity. The attempt to give a specific definition of disability results in a fixed categorization that produces a fixed identity. It connotes a homogeneity that assumes the identities of persons with disabilities are the same. Ben-Moshe and Magana (2014) argue that "disability is fluid and contextual rather than biological" (p.105). Their argument is that disability cannot be defined because it is not static. The concept of disability and the body is evolving; as a result

it is too complex to give a single definition of what disability is. Ben-Moshe and Magana (2014) take it a step further by explaining that due to the complexity of disability, it is easier to define "disability studies than to define disability" (p.106). They define disability studies as "a critical study that takes the constructed nature of disability as its point of entry" (p.106). In other words, they do not conceive of disability as based on fixed cultural or medical definitions, rather they build their perception of disability based on the lived and individual experiences of persons with disabilities. Disability studies looks at the meaning we give to bodies that are different from ours. It is interested in the meaning we give to differences in our understanding of disability (Linton 1998 as cited by Ben-Moshe and Magana, 2014). As much as we try to understand variations, the agency to describe disability should lie largely with persons with disabilities because they embody the lived experiences.

The Body: An Embodiment of Experiences

This project focuses on narratives as a body of experiences rather than the physical body. Some scholars have called the body of experiences the subjective body (Turner, 2009 citing Mauruce-Maleux Ponty). The subjective body reveals the personality of persons with disabilities that may be overlooked when we focus on the objective body, which is what is seen on the outside. For example, for a blind person the objective body could be an individual walking with the aid of a guide dog. Or for an individual in a wheel chair the objective body is the individual in the wheelchair. The problem with conceiving the identities of persons with disabilities with the objective body is that it limits our perception. We see only with the immediate external visual image on first sight and may base our perceptions of that person on that mental image, based on perceptions.

Sometimes able bodied persons attempt to understand the disabled body using able bodied experiences. As a result, the disabled body is scrutinized by the ableist glare which questions the disabled body for its appearance (May & Ferri, 2002). This scrutiny sometimes

is a distraction that keeps the one staring from moving past the physical body to understanding the person as an individual. It is therefore imperative to instigate a shift that enables a difference in the way people perceive persons with disabilities.

With a shift to the subjective body, the experiences of persons with disabilities stand as real life stories that represent their individuality and abilities. The subjective body offers alternative narratives and images of the identities of persons with disabilities. In this project, I work with persons with disabilities to make their experiences available to attempt to compel a shift in people's perception from the objective to the subjective body. In the next section I look at how persons with disabilities are advocating for themselves using their physical bodies in order to set the context of work that is already being done. In the following sections I discuss other methods that have been employed to present the experiences of persons with disabilities and to give credence to their experiences as a subjective body.

In presenting experiences, the subjective and objective body cannot be separated because discussing one brings in the other. For example, in this project when students speak about their experiences, which I refer to as the subjective body, they always speak about the objective body so these two cannot be separated. Rachel, a participant in this project, wants to speak about her experiences and advocate for herself using her physical body because she wants people in the society to see and be aware of the accommodations she needs. However, Nika does not want immediate attribution to her disability. Although it comes up in the discussion, it is not the first thing she wants to talk about or be singly identified as. As a result, speaking and talking about the body takes different forms depending on the individual and I explore this in detail in the following sections.

Agency in Disability as a Performance and an Art

The subjective body constitutes experiences that affect the agency of the person with a disability. Earlier I emphasised the importance of persons with disabilities being able to

speak for themselves. Some scholars have argued that disability is creative (Kuppers 2014) and is also a performance (Sandahl & Auslander, 2005). Persons with disabilities as they live daily in the society are performers of their disability as they are being stared at as able bodied persons try to figure out and understand their difference. The reaction of persons with disabilities to the gaze and stares moves them from being objectified to also actively participating in a performance because they are actively contributing to people's construction of meaning about their bodies (Sandahl & Auslander, 2005). This short quotation about Ed Roberts, the founder of the independent living movement who was quadriplegic shares insight into how the reaction of persons with disabilities to stares and gazes contribute to the process of meaning making about their bodies:

> As he was lifted from the car, he had felt the staring eyes of his schoolmates. Staring was what he had most feared. But the stares that day were not looks of disgust. Those who were discomfited had averted their eyes. Instead, these were stares of fascination and excitement, as if Elvis Presley had suddenly descended upon the school. "It was like being a star," recalls Roberts. "So I decided to be a star, not a helpless cripple." (Sandahl & Auslander, 2005, p.3)

> Here Ed, after being homeschooled for years, decides to return to a public high school

to continue his education. The scenario above describes the scene when he first sets foot in the school. His onlookers, probably not used to seeing someone with quadriplegia in school, stare at him. Ed's reaction is to read their stares as stares of "fascination and excitement" positioning himself in his thoughts to be a celebrity like Elvis Presley and not a weird body that is being looked at. The process of allowing himself to be looked at and as a celebrity move him from being in the object position to being a performer who is contributing to meaning about his body (Sandahl & Auslander, 2005).

Two scholars with physical disabilities have also enacted their agency by using their bodies for performances. Petra Kuppers is a scholar who does work alongside Neal Marcus on disability. She does situational performances by taking her body to certain locations and making presentations there. She draws attention to the body by using it as a channel to express her narrative. In a presentation at a critical disability event entitled *Art, Disability, Images, Bodies,* Kuppers (2014) emphasizes disability as an art and as creative (Sandahl and Auslander, 2005). A major theme of Kupper's and Marcus's work is to use physical leaning to signify and create a sense of community. In her workshops and performances she requests the audience to hold each other's hands and lean on the next persons' shoulder, forming a connection of hands and physical bonding across the room. Their stance is that notwithstanding our physical identities, we all need each other. The connection of hands and leaning is used to show that we need to depend on each other to exist as a community. As such, persons with disabilities and able bodied persons need to depend on each other to live in the society.

Mary Duff, an artist who cannot use her hands as a result of thalidomide in her body, sees her art as a way of engaging the world. She paints with her big toe. She mentions on her blog that painting with a disability is challenging because it affects the speed of her work and the result of her art but she feels the achievement when she gets her work done (Duff, 2015). Her arts include but are not limited to landscape paintings that reflect nature and studio paintings and portraits of individuals in restful positions or in poses as if waiting to be photographed. The making of these works is a reflection of her experience of resilience in being an artist with a disability. In the "about" section on her blog she admits the difficulty of painting with her disability but that does not keep her from getting work done (Duff, 2015). Since she cannot use her hands, she discusses on her blog that her left big toe is her greatest asset for painting. The use of her left toe signifies her perseverance to get her work done. In

an acceptance speech for an award, she discusses how her art also represents an opposition to the perception that the disabled body is unable to do productive work. Her art is an expression of her agency that bears with it her experiences of being a painter with a disability (Duff, 2015).

CHAPTER 2

METHODS

For this project, I am working with students with physical disabilities currently advocating for better accessibility at SIU and in Carbondale. Participants were selected using purposive sampling because this project focuses on the experiences of four students advocating for better accessibility at SIU. There was also one more participant who started the project but did not continue for personal reasons. I am working at SIU because I have access to the students with disabilities who attend SIU due to previous interviews and meetings we have had together. From the literature review, I have identified that there is need for persons with disabilities to speak for themselves about issues that affect their individual disabilities for themselves. Since this study is focused on exploring inaccessibility and its effects on students with disabilities at SIU and Carbondale, my research questions are the following:

- For the students with disabilities at SIU interviewed here what does inaccessibility mean?

- What are the effects of inaccessibility on the students with disabilities at SIU interviewed here?

I have used in-depth, semi-structured interviews and autobiographical accounts as my methods. For the autobiographical account I requested that participants give a specific account of their lives in order to use the account or accounts to express themselves regarding their experiences and to identify from their discussions themes that are connected to inaccessibility and how it affects disability. Participants were able to choose to share their accounts as an audio or video recording, a written essay, a piece of poetry, a song or a

drawing. I then used the in-depth, semi-structured interviews to follow up on themes raised in the autobiographical accounts.

I solicited participants from two student coalition groups, AccessAbility and the Accessibility Coalition, both of which are focused on advocating for better accessibility at SIU. These groups are open to students to participate. I attended the coalition meetings and invited students actively advocating for accessibility from these groups to participate in this project.

Autobiographical Accounts in Ensuring Authorship and Self Advocacy

In this section I discuss the significance of autobiographical accounts in identifying experiences that were most important to participants to discuss. I also discuss the relevance of autobiographical accounts to ensuring the authorship of those who use them. For this project, I requested that participants share accounts of their lives as students at SIU Carbondale to identify from their discussions themes that are connected to inaccessibility and how it affects disability. The autobiographical accounts served as another layer in addition to the individual interviews in identifying what was most relevant to participants in their experiences as students in SIU. Participants discussed specific issues of inaccessibility in the autobiographical accounts and also talked about them in their individual interviews. This consistency in discussions showed that issues of inaccessibility were relevant to participants in this project.

Similarly, through autobiographical accounts participants could share their experiences using various forms of art such as a song, poem, drawing, audio or video. Three participants decided to tell me their experiences while one participant wrote out their account. The option to use different forms of art was to allow participants to present their experiences and voices in a way they felt comfortable. I then incorporated the information from the autobiographical accounts with the interviews during my analysis. I use this method to ensure

their authorship and also to recognize that my voice will be part of these stories as I am also part of the structuring and arrangement of these stories in the research paper and in the documentary. As Atkinson, Coffey and Delamont (2003) discuss, this leaves more responsibility on me as a researcher and media producer to work with those participating in this study to ensure that they are presenting their experiences themselves through the writing and production of this project.

The autobiographical account is different from an autobiography because it is initiated by the researcher. It is the researcher who requests accounts of a person's life to answer a research question or an emerging theme in their work (Atkinson, 1998). For the purpose of this project, I am employing the autobiographical account to ensure that students with disabilities are actively part of presenting their experiences as students with disabilities at SIU. Also, I employ this method because I can understand through the experiences they share what inaccessibility consists of and its effects on their lives. The process of consciously and actively authoring a narrative puts the author in a reflexive state that brings to mind experiences they may not have yet reflected on and may also be relevant to the study being carried out. It makes the author consciously process the formation of their lived experiences and identity (Atkinson. 1998).

Individual Interviews as Reinforcing Authorship

In my previous meetings with participants, I have seen that though they share some commonalities, they are also very distinct. Each student is unique in the way his or her identity is expressed. I get at these distinctions through the individual interviews by getting participants to discuss topics that are relevant to them.

I also use the semi structured interview to follow up on themes from the autobiographical account method. This project employs the qualitative approach to

interviewing which emphasises thick description of occurrences requiring that the interviewee reflects on past and present experiences (Kvale, 1996). In the process of doing so the interviewee may also come upon some ideas that they had not considered prior to the interviews (Kvale, 1996).

Fontana and Frey (2000 citing Bradburn, 1983) point out that there is a limitation with interviews because the researcher can drown out the interviewee with his or her voice. The semi structured interview, however, requires that the interviewer is more neutral rather than asking leading questions, which gives the interviewee ample room to share their responses (Fontana and Frey, 2000). In the following section I discuss the relevance of the audio form as a tool for enacting agency for those who use it as a medium to tell their stories.

The Audio Form as a Method for Delivering Narratives and Enacting Agency

In this section I discuss my reflection in producing the audio documentary and also the radio as an audio platform that has been used for advocacy. I also discuss my role and purpose in using the documentary form. I use themes identified from the interviews and autobiographical accounts to guide my editing of the audio documentary. The audio documentary will be available online for use by participants and RSOs advocating for accessibility issues and by those who are participants and collaborators on this project.

I am presenting the experiences of students with disabilities participating in this study as an audio documentary because my aim is to draw attention to their experiences as students and individuals at SIU and in Carbondale. I chose the audio form because it is known to be used by historically marginalized groups to present their voices on issues that are largely not discussed in the society. While editing the audio documentary for this project, I have been focused on ensuring that the voices of participants are reflected in a way that presents their conversations as real and something that can be connected to. I have also had to make decisions on what to include and what to leave out. Such decisions are sometimes hard to

make because it seems everything is relevant and should be heard. In making this decision I have tried to choose what listeners, the SIU and Carbondale community, can connect to by looking at what is present in our lives though it may take different forms. Reflecting over the interviews I realised that everyone wants to be recognized as an individual with intelligence and a functioning member of society. I shape the stories in the audio documentary to follow this tangent, detailing the experiences of each person to reflect how issues of inaccessibility make participants feel they are not part of society. I also reflected on whether or not to include my voice in the documentary. I understand that my editing and interviewing also reflects that I am co authoring these stories with participants in this project. As such, I included my voice reflecting my stance as one who is there trying to understand what their experiences are like and who is also willing to learn ways able bodied persons like me can be part of ensuring that persons with disabilities feel that they are a part of society.

As I interacted with the equipment such as the microphones, editing software such as Protools and doing voiceovers I actively reflect on discussions in interviews and tried to put myself in a state of mind where I could imagine some of the things discussed in order to appropriately represent the experiences in the audio documentary. While editing I have sought to finesse the editing to ensure the conversations sound real as they have been told to me. I have realized that storytelling about peoples' lives cannot be done by any equipment or editing software but by people who care and are seeking to make a change.

On radio and advocacy. As stated earlier, one of the reasons I chose to present these experiences as an audio documentary is because I want people to actively listen and feel they are a part of the stories. Other platforms can do this but the radio, specifically independent and community radio programming, was born out of advocacy for independent story telling that reflects diversity and the needs of the community. Opel (2004) discusses the history of the battle for Low Power Frequency Modulation (LPFM) small-scale radio stations and the

advocacy that backed this up. According to Opel (2004) the Federal Communications Commission (FCC) played a key role in bringing LPFM to the fore, however he also argues that the presence of advocacy from the National Lawyers Guild, Civil Rights Commission and other organizations pushed forward the enactment of the bill that made LPFM a reality. LPFM was established for non-commercial radio programming for local communities, and any organizations that own media outlets for profit were not allowed to own any LPFM stations. Although this sparked a lot of resistance, especially from the National Broadcasting Association (NBA), the FCC kept its stance. The FCC maintained that LPFMs are for the representation of voices that had previously not been heard in for-profit media. LPFMs were also to be within the vicinity of the local community they represented to ensure that they could include diverse voices from various communities (Opel 2004). Opel (2004) notes that the establishment and the procedure to establish LPFMs is contrary to the way the broadcast market looks at the business of media which is focused on ratings and large audiences. This difference from the norm and the presence of LPFMs reflect that the voices and demands of advocates for community programming were heard and paid attention to (Opel, 2004). The establishment of LPFMs is an important historical point of reference in a long history of grassroots radio as a platform for marginalized groups to present their voices.

Similarly, Luther (1997) discusses the utilization of the shortwave radio transmission by women who were part of the Feminist International Radio Endeavor (FIRE) to speak for themselves on issues of abuse and marginalization in their individual countries. This process started when some women held a conference in Miami, USA in November 1991 to discuss issues of marginalization that they face in their individual countries (Luther, 1997). After the conference these women sought ways to continue their discussions and were able to do so by using shortwave radio transmissions. Luther (1997) describes how short wave transition

stations are cheap and accessible compared to the FM and AM bands. With this strategy members of FIRE could produce their own radio programs where they explore issues relevant to them.

The leaders of the women's conference joined the peace and radio network and came up with their own shortwave radio station, FIRE, in which participants from different areas of the world could report on issues by tape recording sessions to be aired on FIRE. By being connected to FIRE, even those women in remote areas of the world felt connected to a larger community of women, which boosted their confidence to speak on issues of abuse which some of them had previously been silent about.

With the students participating in this study the audio documentary and research paper stand as a forum for presenting their experiences as individuals, students and people living with disabilities. The lack of technological expertise in radio production has been highlighted by scholars as a key issue that prevents individuals, activists and communities from sharing their stories (Dunbar-Hester, 2013; Luther, 1997). Dunbar-Hester (2013) discusses how for activists who use radio as their space for activism, lack of technological expertise often keeps them from meeting their campaign or political goals. Similarly, Luther (1997) discusses how limited knowledge on how to produce their own radio programs is a major issue.

Despite these challenges, the fight for community radio programming signifies the importance of radio as a platform for reaching out to and connecting people at the grassroots. Community and independent radio programming is also a form that allows for the sharing of alternative stories that are not commonly present in the mainstream. The audio form allows individuals to express themselves openly at times, almost as if the gadgets and equipment are absent. In conducting interviews with participants, they connect with me and this helps both of us to ignore the equipment and share their stories as if the equipment is not there. Compared to most camera and lighting equipment, radio equipment gives an illusion of privacy, as if the

conversation is only between the interviewer and interviewee. This allows for the creation of a safe space between the interviewer and the interviewee that may also exist because neither of their faces are seen. Because the radio has the advantage of anonymity it allows its users to role play and speak freely.

The audio form has the advantage of triggering the mind to imagine and think. It has the ability to draw the attention of the listener and also make him or her listen actively. Because there are no distractions in terms of visuals, the mind is employed to create an image of who is speaking and what is going on. The audio form has the capacity to do this because the listener is given the chance to clarify his or her own imagination or thought himself or herself. I employ this method because I want the audio documentary to invite the audience to listen, actively, by imagining as they listen what the experiences of participants are like.

Analysis of Interviews and Autobiographical Accounts

I analyzed the interviews and autobiographical accounts by identifying themes in each document and also looking out for intersections where the experiences of participants are similar and illustrating that in the themes. I analyzed each interview by reading line by line at least twice, coming up with themes each time I analyse. Some of the themes I identity I noted using the words of interviewees as stated in the interviews or autobiographical accounts. This style of preserving themes with the use of interviewees' words is known as In Vivo coding (Saldana, 2008) and I employ it to preserve the richness of participants' words as they describe their experiences. I also compare themes that are consistent in my repeated analysis of the individual interviews to come up with final themes for each participant. Also, to explore the intersections of their experiences, I look at themes that are consistent in all the interviews to see what is common to all participants. In the next section I discuss my analysis and interviews.

CHAPTER 3

THEMATIC ANALYSIS

Two major findings from the analysis of interviews and autobiographical accounts are my participants understanding about people's attitudes towards them and physical structural issues at SIU and in Carbondale as affecting the lives of project participants and creating situations of inaccessibility for them. As I discuss the themes, I discuss specifically how my participants understand people's attitudes and the structural issues they face, and how these create situations of inaccessibility for students with disabilities at SIU. Before presenting the themes that emerged, I will introduce my four participants briefly.

The Interviews
Nika

Nika is a resilient young woman who does not take no for an answer. She discusses with me how when she gets a no from people it only motivates her to do more. She describes her personal experience of going through over 25 surgeries on her eyes and then losing her eyesight, and how this enabled her to develop strength to be persistent and go after her goals despite limitations that may arise. She identifies as being blind while emphasizing that her blindness does not make her any less of an individual than anyone else. We have had more than five meetings and conversations in which we discuss her experiences as a student at SIU. Nika has been very open in discussing her experiences with me and she invited me to her home where I met her friends and her guide dog Kia. She says she is open in order to clarify assumptions people have about persons with disabilities through sharing her personal experience of being blind (personal communication, February 29, 2016 & March 5, 2016)

Rachel

Rachel is a scholar studying intercultural communications at SIUC. I have also had five conversations with her through the course of this project. The first was in Fall of 2015 when I told her about my intention to base my project on exploring and sharing the experiences of students with disabilities at SIU. She was very excited and also shared suggestions on how we can go about presenting personal stories on experiences of inaccessibility. She introduced me to a professor who had done something similar in the past and will be very interested in our project. Reflecting on our interaction in the Fall and our interviews she says, "I felt that my experiences could do more. Rather than just being experiences, that they could be connecting to other forms of thought" (personal communication, March 4, 2016). "By other forms of thought" she refers to connecting her experiences to the research of other scholars in the field of intercultural communication. She sees her course of study as a means of contributing to the field of intercultural communication as well as a platform to articulate and academically explore her experience as a student with a disability (personal communication, February 26, March 4 & 11, 2016).

Nathan

Nathan is a young man interested in being an anchor or as a radio or television broadcast journalist. He dresses professionally to our interviews and is excited at the sight of the audio equipment I use to record the interviews. Although he has been discouraged by family members and counsellors from pursuing his goals he remains dogged in his goal to be a journalist (Nathan, personal communication, March 4 & 11, 2016). We met for seven conversations through the course of this project in which he has consistently expressed his desire to pursue his goals without having to subscribe to "social norms" of what he should be (Nathan, personal communication, February 12, 19 & 26, March 4, 11, 19, 25, 2016)

Joshua

I met with Joshua only one time after which he was unavailable for interviews. Nevertheless, our discussion was useful and I have used it a few times in this analysis. In our first and only discussion he speaks with much passion about the transportation challenges for students with disabilities at SIU and the need to attend to them immediately. He identifies as a student advocate and is active at the Women's Center in Carbondale, volunteering in workshops and trainings that offer support and training for people of marginalized communities (personal communication, February 12, 2016)

For the students with disabilities at SIU interviewed here what does inaccessibility mean?

In this section I discuss my first research question which aims to explore what inaccessibility means to participants in this study. I draw from the interviews and autobiographical accounts to establish how each person describes inaccessibility. Participants mostly describe inaccessibility by discussing what accessibility means to them. A key point that arises from these discussions is that inaccessibility at SIU and in Carbondale occurs in the absence or limited availability of physical facilities for students with disabilities as well as in people's attitudes, including some professors, students and other members of the community, towards students with disabilities.

Nika discusses what accessibility means to her and gives some perspective on the difference between accessibility and equality. She says:

> The difference between accessibility and equality. Pulliam is the oldest
> building on campus . . . There is only one door you can get into without using
> steps so for anyone that's using a wheelchair they must use this one entrance
> and exit. This entrance and exit is on the ground floor so it takes you
> immediately to the basement but to get to, to the elevator you have to go

elsewhere. So the difference between equality and accessibility is you know there is four or five entrances with stairs but there is only one with capability for a wheel chair. And it's one of those things where, yes okay its accessible but is it equal? And I know that realistically things that have already been built and need to be modified cannot always be equal so accessibility is the best that they can do. So that's fine. (personal communication, March 5, 2016)

With Nika's discussion we see that to her, accessibility is the availability of accommodations[2] such as elevators for wheel chair users. However she goes beyond defining accessibility as equality, pointing out that the focus for improvement should not be on accessibility alone but also on equality because equality requires more than accessibility. As a result, focusing on accessibility alone does not offer a full grasp of the situation. Using Pulliam as an example, if we focus on accessibility we miss the fact that the presence of one elevator at one location limits the access students with disabilities have to the building.

Rachel defines accessibility as "ease of access like people of the general population" (personal communication, February 26, 2016). Again what we see here is not the availability of the accommodation alone but the convenience to access and use such accommodations. This points to the importance of equality because of the comparison to the "general population," emphasising again that not only should physical facilities be available but they should be easy to access. Using Pulliam again as an example, this means that instead of the presence of one elevator there should be elevators at different ends of the building to make it easier for wheelchair users to get into the building.

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[2]The Americans with Disabilities Act defines accommodations as "any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities" (29 C.F.R. app. § 1630.2(o)).

Nathan describes accessibility as "Me being able to get where I want to go..., where I want to go. I mean I will like to be able to live where I want to live" (personal communication, March 11, 2016). Nathan's desire is to live in a house that is not for only persons with disabilities. However, it is difficult to find an apartment that is adequately suited for his disability. He explains that though there are houses for wheel chair users, they are designed for people who are very limited in moving around independently which is not the case for him because he can navigate his apartment with his walker. As such, there are houses with accommodations for wheel chair users but they are limited in Carbondale, especially houses that accommodate both able bodied persons and wheel chair users. We see here again a pointer that the availability of more accessible facilities should be the focus when we think of accessibility.

As a result, these definitions give context to the use of the term "accessibility" in the rest of this document. From the discussions we can see that what accessibility means for each individual is different but still centers on the availability of more accommodations and facilities for students with disabilities at SIU and in Carbondale.

What are the effects of inaccessibility on the students with disabilities at SIU interviewed here?

In this section I discuss the effects of inaccessibility as discussed by students with disabilities. I discuss this with five themes and use quotes from the interviews as the heading for two of the themes. What is discussed below reflects cases of inaccessibility that are shared by all participants and also those that they have experienced and continue to experience individually.

Difficulty accessing physical facilities: limited access to privacy

I borrow this theme from Rachel who describes accessibility as "ease of access to do things like people of the general population" (personal communication, February 26, 2016).

Agreeably there are things the able bodied population do seamlessly which for some persons with disabilities can be difficult if the environment is not structured to allow them to do so. Rachel discusses how the difficulty accessing physical facilities leads to her having limited access to privacy at SIU. She says a lot of the doorways are small so it is difficult to fit her chair through them. She tells me that because she has to meet her professors in the hallway to discuss things, "I won't have the same access to private information as someone else will have" (personal communication, February 26, 2016). Similarly Nika describes the lack of privacy while trying to use the bathroom in Lawson, the Student Center and Quigley:

> There are currently bathrooms that have curtain like shower curtains . . . . I addressed it to administration . . . . there is no lock it's a curtain that doesn't even cover the entire door . . . . I addressed it on the privacy issue because I have a dog that sticks her head out. (personal communication, March 5, 2016).

The lack of privacy in these incidences limits Rachel and Nika from being able to conduct simple day-to-day activities as able bodied persons are able to do. Again it leaves them feeling like they are living on the margins of society with limited access to basic facilities. While conducting my interviews for this project, I also found out I could not use one of the audio studio spaces in the Communication Building for interviews because the doors were too small to accommodate a wheel chair. This was also frustrating to me because I found it difficult to find a space that was private and had wide enough doorways or ramps for a wheelchair user to access. The limited access to privacy on campus marginalizes these students from being able to live freely on campus. More attention needs to be paid to the physical structuring of rooms in buildings to accommodate students with physical disabilities on campus.

Susceptibility to physical danger

Here I refer to my interview with Joshua in which he points out the dangers of inaccessibility especially in reference to transportation for students with disabilities at SIU. Joshua shares with me how "the DSS [Disability Support Services] van does not work on weekends and does not work late at night leaving students with disabilities vulnerable. Female students are open to assault and even male students. Something needs to be done about the bus like right now" (personal communication, February 12, 2016). Rachel also confirms that a friend had called DSS on her behalf to be picked up, and she says "they were very rude to him and they were like well maybe we can pick her up but we don't know when" (personal communication, February 26, 2016). Both Rachel and Nika agree that DSS has been helpful to their stay as students at SIU so these statements point to current issues that need to be addressed. The current budget crisis at SIU may be one of the reasons for the limited provision of transportation services, however the effect of this is that it leaves students in a position where they are out alone especially after classes at night with no alternative but to consider less safe ways to reach their destination. This is especially not safe during the winter period, as Joshua explains that when it snows the sidewalks are sometimes icy and wheelchair users sometimes have to take their chairs out onto the road (personal communication, February 12, 2016). This leaves them susceptible to being hit by a vehicle. In fact Rachel has experienced the danger of almost losing her life twice. One incident occurred where she skidded off a slushy sidewalk on a snowy day and was almost hit by a car (personal communication, February 26, 2016).

Some of these issues are complicated and difficult to resolve immediately probably due to the financial situation at the university at the moment. However, these issues leave students with disabilities in a vulnerable position where their safety is reliant on the decisions that the administration makes concerning services at SIU. As a result, the administration needs to strongly consider students with disabilities when making such decisions.

Professors' attitudes contributing to limited access to academic success

In this section I continue to discuss the effects of inaccessibility, specifically how some professors' attitudes have resulted in situations of inaccessibility for participants in this study. For example, Joshua was not allowed the use of a research assistant in one of his classes because the professor considered this an unfair advantage over other students. However, he explains to me that the research assistant only helps him gather resources and a friend explained to him that this is the same as making use of a reference library (Joshua, personal communication, February 12, 2016). Some professors do not understand the relevance of note takers and research assistants for students who require them. Using Joshua's example and understanding that a research assistant is like using a reference library clarifies that the student is using the same resource as others. As such, professors who are reluctant to permit accommodations for students with disabilities should seek to understand the essence of the accommodations from the student's perspective. Rachel cites an example where she got a lower grade in class because she sat on the floor during class sessions:

> In class I had a lot of back spasms...I'll sit on a floor because that took pressure off my spine. I will engage in class I will do my work. I got As in everything but when my participation came in I guess I got a C or a D in class participation because the professor felt I was disrupting the class by sitting on the floor. He emailed me back and told me he took off participation points because I sat on the floor in class. At the beginning of the class I had told him I'll sit on the floor (Rachel, personal communication, February 26, 2016)

Again Rachel suggests that though she did all the work required she lost grades because the professor understood her act of sitting on the floor as a disruption. Again this points to the fact that the professor may be seeing the situation from his own perspective not from hers, in which she did so because she was in pain and needed to attend the class to excel

academically. It is important for professors to understand that allowing students with disabilities accommodations in class contributes alongside other factors to their academic success.

Invisibility: seclusion, silence and value

Emerging from the themes are **invisibility** as a theme and silence, seclusion and value as subthemes. The feeling of invisibility comes from participants feeling absent because of people's attitudes towards them, decisions made by the administration and also the physical structuring of buildings at SIU. I refer to my first one-on-one in-depth interview with Nika where she describes her animosity towards her cane. "I hate my cane," she says (personal communication, February 8, 2016). After carrying out a test with a friend of hers she found out when she is with her cane people react to her differently. "When I'm out in public, people see my cane they don't see me" (personal communication, March 5, 2016). She describes an experience on campus where she was walking towards a group of people talking and as she moved closer the conversation ceased. This left her confused about where to go because she relies on the sounds coming from people to avoid bumping into them. Similarly, when she goes out to eat with her partner she describes how the waiters or waitresses ignore her and ask her partner for her order. On the contrary, she describes having a completely different reaction when she is without her cane because she is treated as "normal" and does not feel ignored or invisible (personal communication, February 8 & March 5, 2016). When she is ignored, Nika describes feeling how "not only am I blind, now I am deaf and dumb." The attribution of "deaf and dumb" here symbolises a feeling of disability put upon her more than her own physical disability which has the effect making her feel **silenced** because she is not paid attention to. It has the effect of suggesting to her that though she may be present in the social context her physical body and also her opinion are not relevant.

For Rachel the feeling of being invisible comes from the way the buildings at SIU are physically structured. She says "while my ideas are accepted, my body is still not welcome because my office doors to my office are very hard to get in" (personal communication, March 4, 2016). The way the buildings on campus are structured acts as a reminder that the physical environment at SIU was not structured taking into consideration someone like her because of the difficulty it takes to manoeuvre her chair to get into her office, the bathroom and classrooms on campus. Another experience that reinforced Rachel's perception was when she was almost hit by a car on a snowy day at SIU. She describes:

> My day is going fine, everything is kind of a normal day. I was struggling with the ice but then, all of a sudden the next thing I know this car is clearly about to hit me.... The wheels and the front of the car is literally right next to my wheel chair with no space in between. So if that person was not able to stop he would have kept going and I honestly with the way he was going, I, there was a likelihood that I won't be here right now talking to you. That I would have died.... My life could be gone just like that because of really SIUs inability to think about all their students when determining whether students should have school or not (personal communication, Feb 26, 2016)

Drawing from the last phrase, "all their students" is a signifier that she feels she and other students like her are invisible to the SIU administration and due to that absence of recognition her life was put in danger. She buttresses her point by saying that when SIU thinks about students, it thinks about only able bodied students though students with disabilities are also a large population on campus (Rachel, personal communication, Feb 26, 2016).

She discusses later on in the same interview how her classmates and professor have decided to have a chat online with Facetime on snowy days when it is difficult for her to

drive her scooter to school. She said "so I really like that idea and it really makes me feel **value** that people are willing to do those things" (personal communication, Feb. 26, 2016). **The feeling of value** comes from the attention being paid to her concern for safety, being validated by her professors' and colleagues' positive responses and actions to ensure her safety.

In connection with invisibility Nathan consistently talks about wanting to live in a different apartment from the one he lives in currently because he also wants to live with able bodied people. Here I center on a sub theme of **seclusion** which is connected to invisibility as I will explain in detail. This is a quote from our last interview:

> [I]just want to be with as many people as possible because it just kind of seems bothersome to people on the outside world, because I mean every now and then I'll be out on the street somewhere and people will want to know like where do you live. Like a lot of people will assume I'm in a wheelchair I can't do anything for myself I must you know live in a home or have to have help for me 24 hours a day 7 days a week and it's just not that way at all.(Nathan, personal communication, March 11, 2016)

In this statement Nathan points out the assumption that people think he lives in an assisted home which makes him feel secluded from society when he is assumed not to be part of the major population because of his disability. As a result, he does not want to be secluded with the disability community alone because he wants to be ³¹ to interact with people from both the disabled and able bodied communities and maybe also prove people wrong about his living conditions.

The situation of persons with disabilities being in a position of being and feeling invisible, secluded and silenced has always existed historically. Booth & Booth (1994) discuss how persons with learning disabilities experience a "lack of independent

representation" (p.123) because their personal decisions for their lives are not paid attention to or taken seriously. Rather the people in their lives, for instance caretakers, make final decisions for them. Rachel, Nathan and Nika's experiences are representative of those of other students like them, because although they live at SIU and in Carbondale, they feel unseen because of people's attitudes towards them and the physical structuring of facilities in the environment.

"People think you have only disability to offer": assumption, identity, marginalization and inclusion

I borrow the naming of this theme from a comment Rachel made in one of our interviews because it brings into perspective another way in which people's attitudes towards Rachel, Nathan and Nika make them feel marginalized. In the previous theme I talked about invisibility and how students with disabilities feel unseen due to people's negative attitudes and the physical structuring of buildings. Subthemes have emerged of assumption, identity, marginalization and inclusion with which I argue, drawing from the interviews, that in instances when people with disabilities are visible there is an assumption by people that the only experiences they have to relate are about their disabilities, thereby ignoring other experiences that contribute to who they are. Rachel discusses this in more detail in my interview with her:

> While I love going to conferences it seems like every time someone stereotypes me as either a scholar who has nothing to offer but analysis of disability. While disability studies is an academic interest of mine the perception that a lot of people have is that people of marginalized identity groups such as person with a disability can't be in the academy unless they talk about themselves. For instance when I attended the National Communication Association Conference for the first time about two years ago

now, I was really excited that I wrote a paper with one of our PhD students here and got accepted and had nothing to do with disability. Not that I want to distance myself from my body at all but at the same time people think that you can only write about what you are and that's why you are in the academy, you have nothing else to offer. One person walked up to me and said oh you're not in the right room the disability issues caucus is not meeting here, I'm like I'm not presenting at the disability issues caucus. It's not that its bad but why can't I do anything else? Why is my identity so centred on that one characteristic that I don't have any value anywhere else? (personal communication, March 4, 2016)

Rachel's discussion here reveals issues of identity, assumption and marginalization which frames the discussion for this section. She **identifies** as a person with a disability but not being limited to that alone because her disability is not the only thing that makes up her identity. Nika makes a similar point when she discusses how professors single her out in class because of her disability. "I don't call people out because they have dark hair and everyone else has blonde hair. I don't know. It cracks me up because they see me as blind Nika and it's like I'm really just Nika who happens to be blind" (personal communication, March 5, 2016). Here Nika, with the hair colour comparison, refers to her disability as a physical characteristic
 that is part of her identity. Rachel's and Nika's perceptions of themselves versus how people see them demonstrate how they feel that they are sometimes seen as their disability only. That perception is disabling because it cuts short everything else that they are and centers who they are only on their disability. Also it sometimes leads to an assumption that their disability is the only experience they have to contribute to conversations in the society, pre-empting them before they are allowed the opportunity to prove otherwise.

Connecting this to **marginalization**, assuming what constitutes a person's identity is marginalizing because it communicates to a person that they belong in a certain category before they have an opportunity to prove otherwise. With Rachel's examples she was told "the disability caucus issues is not meeting here," which carries a message that she belongs to that group and it seems out of place that she is somewhere else. This sets a boundary on who she is and where she should be and it limits people's opinions regarding what people like her can achieve. During Rachel's second time going to the National Communication Association Conference, a man told her how he is inspired by her presenting. Rachel tells me she finds this problematic because she believes it should not be out of place that she presents at a conference. When people assume that persons with disabilities belong to a certain group in society, that assumption has the effect of limiting their inclusion in different areas of society. I use my conversation with Nathan to buttress my point.

Nathan has a goal to be a broadcast journalist, specifically working in the field of audio journalism. However he has received push back from his family who believe he will be unable to perform in that role because of his speech delay. In my last interview we discuss this and he says:

> My Dad tried to infringe with me that I was never going to make it as an anchor and I was like yea right I'll prove you wrong. But then my step mum came into the picture and she was amplified on a whole new level, I mean just had a cynical view point to everything . . . . Back in 2002 I had finally figured it out that working in the news industry might be a little more challenging . . . . Counsellors wanted me to go into this rehab program because they thought these people were just like me and they weren't . . . . I found that out about a lot of students in chairs, they find out they want to do rehab or stuff but they

find out that's not what they are geared towards. (Nathan, personal communication, March 25, 2016)

From this discussion we see that Nathan and others like him are expected to go into rehabilitation services even if that is not what they wish to study. Nathan's family also believes he cannot succeed as an anchor and he confirms to me later that this is because of his speech impediment. The assumption that Nathan cannot succeed in his goal can push Nathan and others like him into a study field that they may not be interested in because of the general expectation that this is where they should be. When a person assumes what a person with a disability is capable of it limits the individual's mind to see only within the boundaries of the thoughts or ideas about what a person with a disability can do. The great danger in this is that it keeps the individual from thinking of possibilities of how to make the society inclusive structurally to ensure that persons with disabilities have the accommodations to pursue their goals. For instance, Nathan's father believes Nathan cannot succeed as an anchor and this has the possibility of limiting him from seeing possible ways in which Nathan can succeed as an anchor and also keeps him from offering necessary support to his son. Similarly, his opinion may communicate to Nathan that people do not expect him to succeed as an anchor, making him feel in a position where he has to prove people wrong.

I buttress my argument with another conversation with Nathan in which we discuss his goal to be a broadcast journalist and he tells me "It is not an industry you will think typically think of a person with a disability working in much less somebody who has a speech impediment" (personal communication, March 4, 2016). Though he says this not as a form of accusation to me, I was quite taken aback because he uses "you" and further reflecting on it I read that he may believe people generally do not think persons with speech delays can be broadcast anchors. There are many factors that may contribute to his belief, the most obvious one being that there are few people with speech impediments who have made it to be on-air-

personalities especially because being an anchor depends on voice and articulation. It also may be possible that Nathan believes his father's opinion to be representative of what other able bodied persons think about the ability of people with speech impediments to be anchors in broadcasting. Family members, friends, teachers and colleagues through their thoughts and words have a great influence in making persons with disabilities feel included in the society. Inaccessibility stems from how we think of persons with disabilities if we think they are part of the larger population, and what we think they are capable of doing. To have a shift in this thought is possible but would require time because people are not socialised into including persons with disabilities in different areas of society.

Recommendation for SIU and DSS: better communication within systems

While Nathan, Rachel and Nika agree that Disability Support Services (DSS) at SIU is doing a good job they also agree that there needs to be better communication between DSS and students with disabilities as well as between the administration at SIU and students with disabilities. SIU is a huge campus and for the administration to know what issues of inaccessibility need to be addressed, participants in this study believe there needs to be a channel of communication to sustain a consistent flow of communication between students with disabilities and the administration. Although there is the Associate Chancellor of Institutional Diversity who receives and addresses complaints from students with disabilities, it is not the position of this office to go out to check for inaccessible locations on campus. Nika discusses having rubber curtains in the Students Center bathroom that have been there since 1980. And she was surprised to find out that no one ever complained about it before. She says "Nobody every brought that up, nobody ever brought it to their attention" (personal communication, March 5, 2016). We both found it surprising that no one had raised the issue with administration and Nika says one of the reasons why persons with disabilities may not be open to communicating anymore is because when they do attention is not paid to what

they say and there are no results. In terms of communication, Rachel also explains how SIU may benefit from having a person with a disability as part of administration or a representative from DSS to speak at the administrative level for students with disabilities (personal communication, February 26, 2016). She believes this will better ensure that needs of students are represented.

Nathan, Rachel and Nika are members of the Accessibility Coalition and they meet monthly to discuss issues that need to be addressed in the city. Although the coalition also discusses issues on campus, Nika who is the head and spokesperson for the coalition explains that there has been limited feedback to her complaints and as a result she had decided to focus on the city which has provided better feedback. She says "it's sad that I gave up on SIU but I had so much push back and so much 'well we can't do this we can't do that,' 'well we don't have the money' (personal communication, March 5, 2016). Giving credence to the present ongoing budget crisis, SIU may not have the funds to currently make changes to bathrooms in the Student Center or other issues at the moment. However some of the changes that need to be made can be resolved by having better communication with students with disabilities and also taking them into consideration when making decisions for the university.

Taking Lessons from Discussions

The discussion of themes reflects that people's attitudes and the physical structuring of buildings are key issues that contribute to inaccessibility at SIU and in Carbondale. Historically this has always been the issue and a law such as the ADA was established in 1990 to address it. However, 26 years later we see through the findings in this project that issues of inaccessibility still exist in society. The discussions in this project serve as a prompt to indicate that the SIU administration, professors, staff and students as well as the Carbondale community need to be aware of the impact of their attitudes in making persons with disabilities feel included on campus. It is important we note that each person with a

disability is different from the next. As such students, staff and faculty at SIU as well as members of the community in Carbondale need to relate with each person with a disability individually, not totally based on our previous knowledge of other people with disabilities. The desire to be **recognized** as an individual is something common to the discussions of all project participants. This is a good desire that is common to everyone; however the fact that it shows up in this study consistently shows that we need to consciously understand as discussed earlier in the analysis that persons with disabilities are not one group but individuals and should be related to with full recognition of that socially and in the creation and enactment of policy that affects their lives.

The previous discussion on individuality leads me to talk about the perception of the body of a person with a disability. When I started this project I was going to concentrate on the subjective body which I have referred to as the experiences of a person with a disability. Although we talk about experiences in the interviews and autobiographical accounts, most of these experiences are about the physical body. As such, I realised that the physical body which I call the objective body and experiences of a person with a disability which I refer to as the subjective body cannot be separated. They are interconnected. However, some participants like Nika want to discuss their individuality and not always their disability. Others like Rachel want to bring their disability to fore especially for advocacy. As such it is difficult to draw a line between one or the other and have a specific description on what the perception of the body of a person with a disability is or should be. I have seen that coming up with a fixed meaning is not the key, rather understanding how a person with a disability speaks about and describes their own body is relevant. The perception that each project participant has of his or her body also influences how they describe inaccessibility. However, a major observation also discussed earlier is that every participant discusses people's negative attitudes and the limited access to physical facilities as major issues of inaccessibility. As

Nika describes, the presence of a facility such as an elevator in Pulliam does not make it totally accessible if there is only one for the whole building and it is located at the back of the building. For Nika, Rachel, Nathan and Joshua these experiences of inaccessibility leave them feeling unseen and unheard.

In order to address issues of inaccessibility at SIU, students who have participated in this project believe that the SIU administration needs to seek better dialogue with students with disabilities on campus in finding out what structural issues and social issues need to be addressed. Although the university is pressured with budget issues at the moment, participants have discussed how what needs to be paid attention to now is strengthening communication and feedback between the administration and students with disabilities. As discussed in the analysis of themes, this is one of the ways that shows to students with disabilities that they are recognized as being part of the student population on campus. In Carbondale there needs to be more accessible housing for persons with disabilities. The city as well as landlords need to seek creative ways to make accessible housing available. Some of these recommendations may take time to carry out but are necessary to the inclusion of students with disabilities at SIU and in Carbondale.

This project reaffirms that issues of inaccessibility still exist in our society in various forms and are affecting the lives of persons with disabilities daily. It strikes me every time I listen to people share their stories how much they have to go through every day to conduct their activities as students and live their lives. Admittedly, SIU has a history of being accessible however participants feel there is still more work to do to ensure that they have the necessary facilities to make their academic pursuit a smooth one.

Through the course of this project I have learned to listen not just for answers to questions but to make a conscious effort to learn about the lives of participants not just for the purpose of this study but because they have become friends. I have come to understand that

trying to understand people's experiences is not a one-off thing. One cannot dig for information and walk away. It is important to be involved in a project like this because you care and also because you want to see change. It is a give and take process where people tell you about their lives and you tell them about yours too. It was recently my birthday and I received a birthday message from Rachel; I was shocked but also deeply appreciated it.

I thought that we have come a long way from me being anxious at the beginning of every meeting because I was not sure of the right thing to say to us becoming friends. Nathan also saw me in the hallway of the communications building and asked me if I had plans to celebrate because Rachel had told him it was my birthday. I was happy to know that we have also crossed the borders of formality and relate to each other now as friends. I believe all of this happened because I listened and also shared my personal experiences thus making our conversations down to earth interactions.

Future Research and Limitations

A limitation to this research is that I did not have enough time to interview more of the SIU administrators about issues of inaccessibility. For a further study, the perspective of the administration on issues of inaccessibility can be explored more in depth. Also I suggest a forum where there can be interaction between students with disabilities and able bodied persons at SIU and Carbondale to ask questions and further explore some of the issues discussed in this project. This idea came up while I was discussing these issues with Nika. We discussed how a forum would be a great platform for a panel discussion with students with disabilities interested in responding to questions people may have about disability and inaccessibility.

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APPENDICES

Appendix A

HSC Approval Letter

SIU Southern Illinois University
CARBONDALE

HUMAN SUBJECTS COMMITTEE   siuhsc@siu.edu
OFFICE OF SPONSORED PROJECTS   618/453-4533
ADMINISTRATION   618/453-8038 FAX
WOODY HALL – MAIL CODE 4709
900 SOUTH NORMAL AVENUE
CARBONDALE, ILLINOIS 62901

ospa.siu.edu/compliance/human-subjects

HSC Approval letter (exempt)

To: Abimbola Iyun

From: Wayne R. Glass, CRA
           Interim Chair, Human Subjects Committee

Date: February 24, 2016

Subject: *Unpacking Social and Structural Roadblocks to Accessing Ability in Southern*
           Illinois University Carbondale

Protocol Number: 16050

The revisions to the above referenced study have been approved by the SIUC Human Subjects
Committee. The study is determined to be exempt according to 45 CFR 46.101(b)2. This
approval does not have an expiration date; however, any future modifications to your protocol
must be submitted to the Committee for review and approval prior to their implementation.

Your Form A approval is enclosed.

This institution has an Assurance on file with the USDHHS Office of Human Research Protection.
The Assurance number is FWA00005334.

WG:kr

Cc: Lisa Brooten

SIU.EDU

VITA

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Abimbola Iyun

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Bachelor of Arts, Communication & Language Arts, September 2011

Research Paper Title:
Unpacking Social And Structural Roadblocks To Accessibility In Southern Illinois University Carbondale

Major Professor: Lisa Brooten