Research Thesis
The Experiences and Spatial Interactions of Individuals with ‘Invisible Disabilities’.

Submitted by

Hope Sneddon

Towards fulfillment of the Capstone in Geography
Western Oregon University
Abstract: ‘Invisible disabilities’ can be “defined as both mental and physical conditions that are not immediately noticeable by an observer.”¹ These disabilities can include conditions such as hearing loss, chronic fatigue, inflammatory bowel diseases, anxiety disorders and color blindness. This study focuses on the body and looks at how space is made to conform to dominant expectations of how the human body should be. I looked at whether or not an individual’s daily routines in everyday spaces are influenced by their disability and if they feel they have discriminated experiences in certain locations. Data was gathered using qualitative methods, including the use of diaries and interviews. Informants were recruited through personal contacts and networking and kept a diary for 1-3 months. They also had the option to participate in an exit interview. Included in this study are individuals who are a variety of ages, different genders and live in different locations. As the primary investigator who also has an invisible disability, I kept records of my own experiences with the use of autoethnography. By assessing the spatial interactions of those who have an invisible disability we can have a better understanding of the role that geography plays in society.

Individuals with “invisible disabilities” are a marginalized group of individuals who are not frequently represented in research that focuses on the body. While there is research that focuses on people with visible disabilities and their experiences, little can be found on the spatial interactions of those with invisible disabilities. I wanted to do research on the experiences and spatial interactions of these individuals. My intention was not to provide a voice for these individuals. They have a voice and they are capable of using it. Rather my intent was to determine what it is that has kept them from sharing their experiences more openly.

After gathering data from the participants as well as analyzing my own experiences I found that my informants work hard to be conscious of how their bodies or actions are perceived in spaces, experienced frustration and anxiety in relation to their disability and at one time or another they were pressured from loved ones to obtain help or assistance to appear normal.

What is considered “normal” for a human body is socially determined and culturally enacted. It is the individual who tries to conform to those expectations therefore making his or her disability invisible. Space is made with preexisting expectations of how the body should be when in places. My informants report that conforming to these expectations in order to appear normal is going to be exhausting and frustrating.

As the primary investigator who also has a disability I can relate to the experiences of my informants. The majority of my interactions result in frustration and anxiety due to constant expectations to appear normal. I am very conscious of how my body is perceived in spaces and am aware of preexisting expectations of how my body should be presented. I received pressure from loved ones in the beginning stages of my chronic illness. I was in denial about the fact that something may be wrong with my body but my behavior was not perceived as normal and family encouraged me to seek medical attention.
Space and Place:

Doreen Massey writes that “places may be thought of as open articulations of connections’ and ‘identities of subjects and identities of places constructed through interrelations not only challenge notions of past authenticities but also hold open the possibility of change in the future.” Experiences in places are going to be different depending on the individuals. Space is created based off of our relations to others and places are the specific links of relationships. It is in places that my informants and I find ourselves having to negotiate our differences with others. These negotiations are unequal and our invisible disabilities end up not being accommodated but rather we try to accommodate ourselves to others. It is relationships and connections within places that construct the preexisting expectations of how the body should be.

Places are always changing; John Agnew writes that they are made up of “space-spanning relationships, place-specific social forms and a sense of place associated with the relative well-being, disruption and experience of living somewhere.” My informants and I are going to have a different ‘sense of place’ than others who do not have disabilities. Having to negotiate our differences with others is what leads to frustrations and anxiety in places. Agnew goes on to write that place can be seen “as sense of place or identification with a place as a unique community, landscape, moral order. In this construction, every place is particular and, thus, singular. A strong sense of ‘belonging’ to a place, either consciously or as shown through everyday behavior such as participating in place-related affairs would be indicative of ‘sense of place’.” The sense of place that my informants and I experience is in relation to our disabilities.

---

Our attempts at trying to accommodate ourselves to others are going to dictate our interactions and lead to experiences of frustrations and anxiety.

**Literature Review:**

There is current research that relates to my study. However, none of it is exactly the same as mine in terms of topic. Most existing research looks at physical disabilities that are visible and how they affect the individuals’ daily routines. In one case, only women with disabilities were studied. In another case only one male who had HIV/AIDS was observed. The common theme in the research that I found was how disabilities affect an individual’s experiences in daily life or ordinary space and place. This is similar to what I did, except that I included people who are a variety of ages, different genders and who live in different locations. My project contributes to the work that has already been done in disability geography because this is a subfield where the experiences of people are highly valued.

In a 1998 article D.C. Park reviews what was at the time a growing interest in disability studies among human geographers. The article covers the expanding literature of the subject and shows studies that were becoming significant in the field back in ’98. They focus primarily on physical disabilities but touch on mental and intellectual as well. The article reviews the ways in which disability studies arrived in human geography. The first portion of the article covers geography and physical disabilities. Research in this area tended to lean more towards statistics and quantitative methods.

Another part of this article focuses on geographies of sensory impairments. Primarily the deaf and blind are discussed in this portion. The third aspect of this research covers geography

---

and mental health, which focuses on locational dynamics of mental health-care facilities.\textsuperscript{6} The fourth part of the article is the evaluation and prospectus; it discusses literature up until 1998 that covered disability geography. It was found that the literature focused primarily on mental health at first and then later there was an emphasis and interest in physical disabilities.

This article is important because it shows how disability studies grew to become more of a part of geography. The article discusses mental health issues but that is the only aspect of “invisible disabilities” that is touched on.

Nancy Hansen’s research looks at the treatment of the body in disability studies as well as disability geography.\textsuperscript{7} Her article discusses the impaired body in its “flesh-and-boneness” while focusing on everyday practices in everyday places. Hansen shows how the disabilities affect the everyday practices of her participants. The research took place in Scotland and Canada and the participants where only disabled women. There was a focus on bodily practices as well as ‘timings and spacings’ that may depart from what is normal for non-disabled people.\textsuperscript{8} Also highlighted in the article is how the women resist accommodations such as modifying external spaces or correcting bodily differences. To conclude, Hansen discusses the fact that better accommodating disabled people is often neglected. One should not put emphasis on aiding those who are disabled by helping them do things “normally” but instead realize that there can be normality in doing things differently.\textsuperscript{9}


Hansen conducted 40 interviews with disabled women, 20 women in Canada and 20 in Scotland. The disabled women were found for the project through disability support groups, networks of friends and “snowballing”\textsuperscript{10}. Interviews were held in locations that were familiar to the women, and lasted between 30 minutes to 2 hours. The interviews were conversational and loosely structured so as to accommodate for emotions that may be presented from the sensitive material. Hansen found that women felt pressure to come off as normal and to accomplish tasks in a manner that was as close to the way an able-bodied person would perform. This causes a disjunction between the body that the disabled person inhabits and the body that society thinks the individual should inhabit in order to occupy space in a normal manner.

This research relates to my work because it is looking at a specific group of people with disabilities and showing how they interact in everyday spaces. It is different from mine because I focused on “invisible disabilities” as opposed to disabilities that are visually apparent. Hansen uses qualitative methods to gather her information and I did so as well. Illustrating how she conducted interviews was helpful to read and relate to my own research. This article by Nancy Hansen gives the world a chance to see how disabled women are spending a lot of energy trying to fit into society by being what is considered normal. We should realize that there can be normality in doing things differently; if it is more comfortable for someone to do something in their own way then why discriminate against them.

An article by Nancy Worth explains “disability geography as a subfield where the personal is highly valued.”\textsuperscript{11} She highlights the values and risks that come with the personal approach, such as the helpfulness of being an insider and the difficulty with being reflexive and


\textsuperscript{11} Nancy Worth, "The Significance of the Personal within Disability Geography," \textit{Area}, 40, no. 3 (2008): 306-314.
the critical use of one’s positionality. The article supports those with personal experiences of
disability to participate in the field of geography. Worth starts her article by showing the
importance in telling what influenced your decision to choose a research topic or what brought
her to the subfield of disability geography. Worth says that her paper “takes a look at one aspect
of a larger project that examined the value of a geographical perspective in disability research by
tracing the development of disability geography as a subfield, its current interests and its future
possibilities.”

Worth shows the importance of having personal connections with the field. For
every example it can provide a voice for those who do not have a chance to speak for themselves. This
article cites other papers, such as the work done by Nancy Hansen which is mentioned above.

Nancy Worth discusses the tricky situation that geographers have found with distinguishing
between impairments and disabilities. There is an argument over what determines an individual’s
impairment over disability. Some believe that society is what disables the person and their body.

Email was used to gather the thoughts of geographers. 16 geographers from the UK, North America, and Australia were interviewed for this project. Email is cost-effective and
convenient method of gathering the thoughts of the geographers. Since, this was a small scale
project the use of email was effective. Questions such a “How did you become interested in
studying disability from a geographic perspective?” and “Who or what sparked your interest in
geography and disability?” were asked via email.

What was found was that the respondents had very personal reasons as to what stemmed
their interest in disability from a geographic perspective. The reasons ranged from family
experiences to their own impairments or disabilities. The importance in this project is to show

---

that research does not take place in a vacuum; and choosing what to research about and how to go about it is often a very personal decision.\textsuperscript{14} Often the decision to conduct research based off of personal experiences can lead to the showing of how something is missing and there are differences that can be overlooked. One geographer uses “personal experiences to help the reader’s see society and our discipline through others’ eyes. The “intention is not to evoke sympathy or pity but to encourage the reader to understand more fully the environments [she] negotiates daily.”\textsuperscript{15}

This research is relevant to my project because my personal experiences influenced my decision to become interested and involved with disability from a geographical perspective. Having an autoimmune disease shaped how I interact with the world around me and having the ability to show my point of view as well as others with similar experiences is important to me. Combining my experiences with my education and knowledge on this subject can help determine why individuals with invisible disabilities are so quiet about their experiences and spatial interactions.

An article by Edward Hall looks at the social geographies of people who have learning disabilities, a group in society that is thought to be largely ignored.\textsuperscript{16} The article uses narratives of people with learning disabilities in Scotland. The narratives help understand the social exclusion and inclusion of those that have the disabilities. The experiences included being excluded or included within mainstream socio-spaces and the safe spaces that people with

\textsuperscript{14} Nancy Worth, "The Significance of the Personal within Disability Geography," \textit{Area}, 40, no. 3 (2008): 308.
\textsuperscript{15} Nancy Worth, "The Significance of the Personal within Disability Geography," \textit{Area}, 40, no. 3 (2008): 309.
\textsuperscript{16} Edward Hall, "Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion.," \textit{Area}, 36, no. 3 (2004): 298-306,
disabilities have created for themselves.\textsuperscript{17} This research “remains within the context of a state social policy of tackling “social exclusion through the economic and spatial integration of marginalized groups.”\textsuperscript{18}

The method of research used for this project was group interviews. The participants were recruited through the Scottish charity for learning disabilities. The participants met for group interview sessions that were in a familiar location. They were asked about their engagements and presence in social spaces, at home, at work, with friends or family and their experiences, and concerns. In this situation group interviews worked better than individual because it was more of a supportive environment. In conclusion, the article argues that social inclusion provides a context that many people with learning disabilities cannot or will not engage it. Therefore they self-exclude themselves as a result and often create new safe places and a new normality of socializing.

This research relates to my project because it covers a group that is thought to be often ignored. Here, the example of people with learning disabilities is used. I included individuals who have invisible disabilities that range from dyslexia, hearing loss and autoimmune diseases; a group of individuals who are often overlooked or ignored in the study of disabilities. The use of group interviews was interesting in this case, however for my project due to the sensitive material and varying disabilities, individual interviews were more appropriate.

An article by Rob Imrie shows the “spatialities of disability and disabled people’s barriered and bounded lives.”\textsuperscript{19} This paper develops the argument that geographers and scholars

\begin{flushright}
\textsuperscript{17} Edward Hall, "Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion.," \textit{Area}, 36, no. 3 (2004): 298-306.
\textsuperscript{19} Rob Imrie, "Barriered and Bounded Places and the Spatialities of Disability.," \textit{Urban Studies}, 38, no. 2 (2001): 231-237,
\end{flushright}
of urban studies should be more active in the studies of the diverse and multiple geographies of
disability. The article starts out by discussing the history and importance in studying the social
divisions and differences on a city. On page 232 it states that “the human landscape can be read
as a landscape of exclusion.”20 Barriers for boundaries can be physical or representational spaces
that are imaginary. The example of asylums for people with mental impairments is used,
illustrating that it can be a place of refuge from society or a place of incarceration.21 The article
states that “the physical construction of urban space often (re)produces distinctive spatialities of
demarcation an exclusion, from the lack of access to public transport systems to the absence of
visual clues or guides in towns to enable vision-impaired people move with ease.”22 The
relationship between impaired people and particular places is an important focus of this article.
Many architects do not understand users of urban space. Often, places are developed with
standards or dimensions that are fit for an able masculine body.

In conclusion this article shows a study that has documented the “diverse ways in which
disabled people’s lives can be influenced by the intersection between their bodies and broader
socio-institutional attitudes and practices.”23 The article points out that writing in cultural
geography and urban studies does refer to spatiality, identity and difference but often does so
without referring to the impaired body.

I chose this article because of the topic of barriers and borders in relation to the body. It
is an important focus in cultural geography. Barriers or borders can be presented as physical

objects or social constructions either way they can have an effect on how someone with an “invisible disability” interacts with their surroundings.

An article by Isabel Dyck is an introduction about “geographical perspectives and concepts to health professionals in their analysis of disability or chronic illness.”24 The project used geographical literature and social theory while mapping daily routines of individuals who had a disability or chronic illness. Specifically the project shows the daily routines of a man with HIV/AIDS and how his relationship with everyday spaces is always changing. The point of this research is to show how geography can make a contribution to an applied discipline such as occupational therapy. In order for rehabilitation needs to be met the individual needs to be understood in the context of their everyday life. To identify areas of difficulty for individuals their daily habits and routines should be watched and analyzed; that is a main focus in occupational therapy and practice.

The participant in this study was Scott, a man with HIV/AIDS. Scott went through a series of interviews with guided conversation about his daily routines and how they changed after he became ill. The article discusses things that affected Scott’s everyday life; they ranged from the actual spaces, such as his home or neighborhood to the healthcare system in the region he was living. In this case it was British Columbia and the subsidies and medical assistance that was provided in this area greatly influenced Scott’s life as well. The research goes on to analyze Scott’s interactions with his neighborhood spaces and medical facilities.

In conclusion, by talking to Scott about his personal geography interconnections between places and spaces, his material body, his homosexual relations, and his illness were

---

24 Isabel Dyck, "Thinking about Environment: Incorporating Geographies of Disability into Rehabilitation Science.,” Canadian Geographer, 47, no. 4 (2003): 400-413.
illuminated.\textsuperscript{25} The location that Scott placed himself in was strategic. An area where he and his partner could be open and accepted was important. The care unit that he went to for medical assistance was a safe place, a place where stigmatization was absent. By linking spatiality of everyday life and the experiences of illness we can provide individuals with spaces that are more appropriate for negotiating a better life.\textsuperscript{26}

This research is relevant to my project because it focused on an individual with an illness and how his location and interactions with everyday spaces changed once he was diagnosed. I found it interesting that not only were everyday spaces included in the research but the location of the person on a larger scale. In this case, Scott was living in BC, which influenced how he lived his life. That was not something that I would have thought of but being accepting by other members of society or the availability of healthcare is going to be different based on the location of the individual with a disability. All of those things will in return affect how you live your life.

An article by Paula Meth looks at the use of personal diaries as a qualitative research tool within geography.\textsuperscript{27} Women in South Africa were asked to keep a diary for one month and to record their experiences of violence. The article discusses the benefits in using diaries as a method, their use in conjunction with interviews and how keeping a diary can provide a sense of empowerment. Lastly, the paper talks about the limitations that the methodological tool of using diaries could possibly have. Diaries can promote participation and engagement from the respondents. This article is in favor of using diaries and argues that the method gets little attention in academic geography literature.

This article first discusses the benefits with using solicited diaries for research and how they differ from personal private diaries. The use of solicited diaries is common among health studies as opposed to human geography. Solicited diaries are written specifically for a researcher and the informant is aware that the content of their diary will go towards a project that is more complex.

In the case with the South African women, 39 out of 40 diaries were returned and they varied in length. Showing that some people will write a lot and some will not write much at all. The article goes on to illustrate more differences in personal diaries versus solicited. Lastly, the article talks about the method as a way of empowering others and evoking social change. This method allows for voices and descriptions of everyday life to be heard. Diaries provide researchers with a large amount of intensive material and therefore should be considered a useful methodological tool within social geography.

This reinforced my decision to use diaries as a methodological tool. Having respondents keep a diary on a specific part of their lives and certain experiences was an important contribution to my project. This article was helpful with showing me the importance in knowing the difference between personal diaries and solicited. Personal diaries can provide ethical issues and are a tool that is used more in historical geography. The article pointed out useful information to keep in mind as a researcher who is using diaries as a research method.

I asked my informants to keep a diary as a methodological tool; I also kept my own diary. Autoethnography is a qualitative research method that allowed me to discuss my personal experiences and spatial interactions in relation to my own invisible disability.

Sarah Wall writes about autoethnography and how it is an emerging qualitative research method. By writing on your own experiences it can help “extend understanding about societal
phenomenon.” She writes that “auto ethnography is grounded in postmodern philosophy and is linked to growing debate about reflexivity and voice in social research.” It is common within scientific research that the researcher should minimize themselves from the work in an attempt to remain unbiased. The postmodern era has provided us with an opportunity to open up to a wide variety of research strategies. Wall’s article about autoethnography relates to my study because it is a method that I used. She states on page 11, “Ultimately using self as subject is a way of acknowledging the self that was always there anyway and of exploring personal connections to our culture.” That is what I intended to achieve by using autoethnography as a research method.

Methodology:

My study used diaries, interviews and autoethnography. Informants were given diaries and asked to write in them a few times a week for up to one to three months. Each informant was given the same prompt to begin their writing experiences. The prompt states:

“Begin your diary entries by describing what your specific invisible disability is as well as how long it has been a part of your life. From there I would like you to think about how your disability may affect your everyday routines. Pay attention to how you navigate or interact in different spaces. Is it different or the same as others who don’t have an invisible disability? Feel free to write down your experiences and thoughts however you would like. For example, writing them down quickly after something comes to mind or doing a more formal entry at the end of the day. Please aim for 3-5 entries per week.”

The intention for using diary entries as a method for collecting data was to provide a safe place for the individuals to share personal information. In my own experience I have found that it is easier to write about my disability rather than speak aloud about it. The participants did provide personal details and accounts within their entries but they also were very honest and sometimes reflective when participating in the exit interview.

My study had a small number of participants. Five diaries were dispersed but only three participants chose to remain in the study. My informants include a male with attention deficit disorder and obsessive compulsive disorder, a female with dyslexia and a female with moderate hearing loss all wrote in their diaries regularly and participated in an exit interview. A female with extreme anxiety chose not to participate because she felt that writing about her anxieties would be too stressful. Lastly, a female with endometriosis became pregnant, putting the autoimmune disorder into remission and making her ineligible to participate.

Having two individuals that couldn’t participate was something that was unexpected. I chose not to find replacements for the individuals who could not participate. Due to time constraints and a difficulty in finding individuals who have an invisible disability I chose to only use three participants. My informants are identified by their gender, age and location. Their occupations were kept private. However there were instances where the informant referred to their occupations too specifically making the diary entry not eligible for use in order to protect their identity.

Although this was a small scale research study the information that was gathered is significant in that it conveys that the participants analyzed and reflected on their experiences and spatial interactions in relation to their invisible disability. This is similar to the study that Dyck conducted with the informant Scott who has Aids. It was research that focused on only one
individual but it is the focus on linking everyday life and the experiences of illnesses that can provide individuals with spaces that are more appropriate for negotiating a better life.\textsuperscript{31}

The participant with ADD and OCD had the fewest number of entries and was not very responsive in the exit interview. This participant was the most difficult to reach, due to conflicting schedules and time constraints. As the investigator I should have put more effort into engaging this participant. Regular check-ins during the time he was keeping his diary may have led to more complete and thoughtful entries. However, that should not discount the fact that this participant did have entries that conveyed he was conscious of his body and disability in relation to his spatial interactions.

The participant with moderate hearing loss was very motivated and exceeded the number of entries that she was asked to write. She was conscious of how her disability affected her experiences and spatial interactions. Many of the entries were reflective and focused on times where she remembered her disability affecting a situation in the past but she also remained very much in the present as well. The entries and her answers in the exit interview were honest and intimate. The same can be said for the participant with dyslexia. She provided detailed entries that illustrated she understood how to write about her experiences in relation to her disability. This participant was very responsive in her exit interview and seemed comfortable sharing personal details. These two were more responsive and that may have been in part because due to location it was easier for me the investigator to check-in and monitor these informants. Keeping a diary takes a certain amount of discipline. It required that the participants take time out of their personal lives to record their experiences and that was appreciated and respected.

As the primary investigator who also has an invisible disability I kept my own diary. I have an auto-immune disease called ulcerative colitis; struggling with this disease and realizing that it affects my spatial interactions is what provided me with inspiration for this study. It is important to share what influenced a research topic because by doing so it shows personal connections to the field.  

Personal experiences are often kept separate from research. In order to remain unbiased the researcher is encouraged to remove themselves. However, there is something to be said for including personal experiences. Autoethnography provides another perspective for analysis and as Wall writes it is a way for “exploring personal connections to our culture”.

Like my informants I kept my diary for a few months and aimed for three to five entries per week. Writing about my invisible disability in relation to my spatial interactions was not difficult. I found that I was perceptive when it came to experiences that were affected by my disability. Gathering and writing my entries was the beginning process of my auto ethnography and came easily. What I found later determined is that there are difficulties that can arise with autoethnography. Due to using my own personal data I found that coding and reading my entries at a later date than when they were written to be uncomfortable. Although they were my own personal accounts I found the material to be upsetting and I often wished I had not chosen to incorporate the autoethnographic aspect of the study. Like the participant with extreme anxiety I wished I could withdraw from my study. After coding the data I began to accept that this was a

---


part of the study that was necessary. As uncomfortable as it may have been, it added a wealth of material to the subject.

In this study the autoethnography aspect was helpful when it came to coding and analyzing the data of the other informants. There were similarities and differences that could be seen throughout my entries and the others. Having already kept my diary I was aware of the personal and intimate nature of the process when I asked my informants to keep their diaries. Therefore the use of autoethnography allowed for a level of understanding that would not have existed otherwise.

**Coding and Analysis:**

After collecting the data from my informants and reading through the entries, I found that there were similarities and differences that stood out immediately and there were themes that would later come to my attention through the coding process. I began the coding process on the physical copies of the entries. I read through them and wrote notes by hand before putting them into a Word document.

Descriptive coding was the best method for analyzing the diaries and the answers to the exit interview questions. Descriptive coding is known as topic coding, it can summarize in a word or a short phrase and is often a noun.\(^{34}\) A summary description of the entries and answers was the first step of the coding process. There were already similarities and differences that were visible amongst the entries at this point as well as recognition that some of the material was not relevant or usable. Some of the entries were excluded in the next round of coding.

After the first round of coding the data was still in a rough format but was more organized in terms of themes. I transferred the data to a Word document to further organize and analyze. No qualitative data coding programs were used due to the small scale of the research.

study. The descriptive coding was effective because the entries were short and a brief summary or descriptive word was all that was needed. With the data in a more accessible format it was easy to organize and categorize based on the descriptions.

The choice of words and descriptions was the most interesting part of the coding process. While reading through the entries and the interview answers descriptions that came to mind were along the lines of frustration, pressure, focus, inadvertent, control, and normality. Specific word choice came from the content of the diary entries. The participants wrote about their personal experiences and how they were feeling in certain situations. The first round of coding was primarily made up of single word descriptions and not very organized.

After transferring the data and its new descriptive codes into a word document I was able to begin to see patterns and organize. At first it felt natural to group things that were alike. *The Coding Manual for Qualitative Researchers* helped me understand that coding and grouping does not mean that all things have to be alike but there is also commonality in differences as well.  

As I moved on in the coding process I looked at the frequency at which I used certain descriptions, and if those corresponded with other entries. As well as looking at similarities and differences.

By looking at the frequency that certain terms appeared or did not appear I was able to put together some themes about my informant’s experiences. The second cycle of coding required more attention to the content. Saldana writes that “Qualitative inquiry demands meticulous attention to language and deep reflection on the emergent patterns and meaning of human experience.”

---


the coding process I had a better grasp on what my data entailed and how it was going to help within the final writing stage.

Overall the research process was effective. There were minor challenges, such as informants dropping out or my personal discovery that autoethnography is difficult emotionally. However, adjustments were made and it was a learning process. The informants were a vital part of this study. Without their participation and understanding the outcome would have been different. Using qualitative methods such as a diary is not common within research due to the difficulty it can be to find participants that are willing and motivated to write about their personal experiences.

**Discussion:**

After gathering and analyzing the data from my informants and my diary there were a few themes that stood out. The first being that there were repeated entries in each diary regarding feelings of frustration and anxiety. These frustrations took place in public spaces and often included being with other people. My informants and I spend a lot of time trying to accommodate ourselves to others instead of having our disabilities being accommodated for. It can become exhausting and frustrating trying to conform to preexisting expectations about how your body should be or how you should present yourself. Examples of this can be seen in the following entries.

The first is from the informant with ADD.

Nov. 24th - “Yesterday I forgot to take my medication. I was spending the day with some friends and a couple of people I had never met. During the day I noticed I was counting my steps and other things silently in my head. I was in our boat crabbing.”

This informant uses counting as a mechanism to release anxiety. Having forgotten to take his medication he began to count in order to deal with the anxiety. Although he was in a space that
he may have been familiar with, such as his own boat, there were new people that he had never met. The new relationships created an expectation of how his body should be. Whereas, if he had been alone there would be no pressure to behave in a certain way.

The informant with dyslexia deals with frustrations and anxiety on a regular basis. She has difficulties with reading aloud, reading signs, and recipes and often mixes up her left and right. She writes:

December 5th “People around me sometimes notice I count out loud. When counting materials at work it gets frustrating when I take my mistakes more seriously than others so I check and double check. I didn’t appreciate my temp worker talking to me when counting aloud and thinking it was funny. To me when people are not sensitive to others when you might not know if they have a disability or something that prevents them from doing certain things.”

This informant works hard to ensure that she makes no mistakes. In order to do so she must count her materials out loud. This action does not appear to be normal from her temp worker’s perspective and the worker purposely tries to mess her up. In this situation the socially constructed normal action would be not to count out loud and make minimal to no mistakes. The informant has to make a choice here, refrain from counting out loud and risk making a mistake or count her materials out loud and receive judgment from her co-worker. Both actions have consequence and result in the informant feeling frustrated.

Having moderate hearing loss presents a number of challenges throughout daily life. This female informant often finds herself frustrated or inadvertently trying to hide her hearing aids in an attempt to appear normal. Although there are many people who experience hearing loss, most are surprised to discover someone such as this young female informant to have a disability. She writes:
December 2\textsuperscript{nd} - “I also can’t lie down on a pillow or cuddle with anyone because my hearing aids feedback really bad. ….This is frustrating because I cannot really be intimate with people without my hearing aids getting in the way. But if I take them out then I can’t hear much, especially if it’s dark, so it’s kind of a lose-lose situation for me.”

She relies on lip reading as well as her hearing aids in order to communicate effectively. When one or both of these things is compromised her experiences in a place are affected. In this situation she finds that she cannot be intimate with someone because her hearing aids will feedback. However if she removes them and it is dark she cannot rely on lip reading as way to communicate either. Being intimate with someone often means turning down the lights. This doesn’t always have to be in a private setting. Restaurant or bars that want to have a romantic or intimate feel may also have low lighting. That is considered common, however; it gives no consideration to someone who may rely on lip reading as a way of communicating effectively. The sense of place for an individual with hearing loss is not going to be romantic or intimate like the intended experiences that are often associated with restaurants or bars. Instead the informant with hearing loss experiences frustration and anxiety as she tries to fit into the hearing world. Her sense of place is affected by her attempts at trying to accommodate herself to others.

Referring to my own diary I can see situations where conforming to spatially constructed expectations of how my body should be left me exhausted and frustrated. In one instance I write;

November 14\textsuperscript{th} - “I am trying to study in the university center but I keep having to use the bathroom. When this happens I just give up and go home. I can’t unpack my stuff because I can’t leave it unattended in public when I go to the bathroom. Also, after about the 3\textsuperscript{rd} trip to the bathroom in 25 minutes people start to stare and then I get irritated. I want to be able to hang out in the library, coffee shops or the university center to do my studying because it is a change in scenery from my apartment but it just isn’t an option.”

Continuously using the bathroom while in a public setting is not considered normal by any means. There are expectations as to how your body should be when out in public. Anything out
of the ordinary draws looks of suspicion from others. There are aspects of an invisible disability that can be seen or noticed if someone is perceptive enough. However, because the effects of the disability do not conform to the expectations that have been prescribed in a place we often choose to deal with them in private. In my case, I chose to leave the public space in order to avoid the stares from other people. Had there not been people in this place it would have been much easier to accommodate for myself. I left because I felt I was making others uncomfortable even though it was my own body that was not conforming to their expectations. It is a frustrating to feel pressure to not disrupt the so called normality of a space.

Individuals that have an invisible disability may be more conscious of their body or what they do with their bodies. My informants as well as I documented instances where we were focused on the body in order to remain normal. Sometimes an informant would fail to remain focused and found themselves in an awkward situation. The informant with ADD tries to remain conscious of his body and its actions but at times he has found himself unable to do so. He writes:

November 19th - “With the ADD I myself having a short attention span and not a real good listener. Often times I will be in a group setting and I find myself standing up and walking away without actually making the decision to do so. When this happens I usually go to the restroom then come back.”

Standing up and leaving a group setting suddenly is not considered normal however to do so in order to use the restroom is. A group setting such as the one mentioned above is not a comfortable setting for the informant. He inadvertently finds himself getting up to leave, and then he justifies the action with something that is acceptable; such as using the restroom.

In a later entry he has a similar experience where he tries to remain focused but fails to do so. He says:
November 24th- “I shook hands with everyone. I then made a point to shake hands with the person I had never met before. As I was shaking hands with him he looked at me funny and said to me I had just shook his hand a moment ago. I could not remember shaking his hand. I realized I had gotten distracted and was not able to stay focused enough to remember who I shook hands with.”

This is another example of how the informant tries to remain focused on what his body is doing. When he fails to do so and shakes the stranger’s hand a second time he has received a look of confusion. How he handled this moment is unknown. Surely this situation has happened to others who do not have an invisible disability. However with someone who does; these sorts of things are going to happen frequently. If you are constantly trying to remain focused on how your body is behaving chances are you will not successfully do so all the time.

The informant with dyslexia knows she mixes up numbers sometimes but doesn’t always catch when she makes a mistake. She relies on others to pick up on it, whether that is someone that is close to her or a stranger in a public setting. She tries to remain conscious and focused to minimize the amount of mix ups that may happen but sometimes they are inevitable. She writes:

November 28th- “Waiting in line at the bakery for a piece of quiche. The lady at the counter asked me if I wanted it to go and I said yes. As she was bagging it up she quickly turned to the register and asked me what the price said in the glass display case. I told her $1.99, the person behind me corrected me saying $1.79. There are times in random places where I don’t notice that I mixed up a number or letter unless someone tells me.”

In this case, the informant was not aware of her mix up. She may try to remain focused and avoid these mistakes but as she stated there are times in places when she won’t notice unless someone tells her. This was also a situation that could happen to anyone. The price she read was more than the intended price so no concern from the stranger was granted. However, if she had mistaken the price as something less the result may have been different. Perhaps they would have accused her of trying to fool the cashier. Luckily this mistake was harmless and the stranger
simply corrected her. One could argue that in this space it is the cashier’s responsibility to know the price. There is an expectation that if an individual has money and can order that they know how to read. This informant knows how to read of course, they just mix things up sometimes. But not every member of society knows how to read and to assume so can lead to the marginalization of these individuals.

Dyslexia can make this informant struggle with things such as following driving directions or recipes. If she doesn’t focus as much as she feels she needs to on the tasks she makes mistakes. An example of this is when she tried to bake a pie, she writes:

November 23rd - “Following recipes can be a challenge for me, when doubling a recipe or mixing up tsp, tbsp. at a glance. I was making a pie and I ended up not only leaving out the sugar but over doing the amount of spices by using tbsp. not tsp. My pumpkin pie was no good. I was really excited to make it but after it came out of the oven I felt sad I messed it up. The only way I figured out I didn’t do it right was that my boyfriend licked the bowl and got this gross tasting look on his face. I wonder sometimes if this happens more often when I’m rushed and don’t focus as much on the tasks at hand.”

The informant admits that she doesn’t know how often she makes mistakes like the one mentioned above. To assume that she can stay focused always and catch her mistakes before others do so would be false. Mistakes like ones this informant makes are seen as inconveniences to the general public. It is expected that she and others who have invisible disabilities try their hardest to avoid or catch these mistakes but in reality these mistakes are a part of their everyday lives.

The ways in which I focus on presenting my body is different from someone who has ADD or dyslexia but what remains the same is that we all are conscious of how our actions are going to be observed by others around us. There are many spaces that require my full attention to focus on controlling my body in order to conform to what is expected in that situation. One of my diary entries illustrates that.
“This morning I sat through my class in terrible pain. Willing myself that it was only 50 minutes, “You can make it, you can make it” I have no idea what the lecture was about but he takes attendance so I had to be there.”

In this situation I was in a lot of pain. I wanted to squirm around in my seat, and I really wanted to run out of the classroom. I did not do either of those things; I just sat still, and focused intently on remaining normal. Normal in this space was facing forward and eyes on the professor. Due to the short duration of the class I chose to stick it out. The professor took attendance and therefore I knew I should stay. This isn’t an ideal situation; sitting still and trying to focus on acting as if you are not in pain takes a lot of mental strength as well as physical. It is exhausting. There was pressure in this space to appear just like all the other students. Not doing so would have had consequence such as being marked absent or receiving funny looks from others. The socially constructed idea of normal and how my body should be, kept me quiet, still and in pain.

The participant with moderate hearing loss relies on lip reading in a lot of situations. She focuses on that in order to communicate effectively. There are times when people turn away from her or an environment doesn’t allow her to see everyone’s face. Sometimes she forgets her hearing aids and only has lip reading to rely on. That can be difficult and requires her full attention. She writes:

December 2nd. “Today I left the house without putting my hearing aids in and I was headed to class. Luckily, my friend knows about my disability so she can help “translate” if I can’t hear something. I am also lucky that my teacher is loud enough that I can hear him without hearing aids. I am always so amazed at how bad my hearing is without hearing aids and how much I wasn’t hearing before I got them. I felt awkward when I got to class because my friend wasn’t there yet and the lady that was in the room was on the other end of the room from me. She kept talking to me, but her voice sounded very far away, so I really had to concentrate on her lip movement. In situations like this I usually try to pretend that I am busy doing something like reading or messing around on my phone so I can avoid any awkward moments of not being able to hear what people are saying or misinterpreting what they said.”
In this situation the informant has to choose between focusing on reading the woman’s lips or appearing as if she is busy in order to avoid misinterpreting. It is considered normal to have informal conversations across a room or space. For the informant this situation makes her feel awkward. It is not known or expected by the woman that the informant has hearing loss. In this space she is expected to focus on reading the woman’s lips in order to try to communicate. If she does not do so she could appear to be rude, therefore resulting in consequence due to something that she cannot control. My informant chooses to accommodate for the woman and in doing so causes my informant to feel uncomfortable and not confident in communicating effectively.

Before starting their diary each informant was asked to write about how long they had their disability as well as provide a brief summary about what their invisible disability is. In each of their summaries they eluded to receiving pressure from a loved one to get help. In the case of the informants with ADD he states:

“Approximately 4 years ago I went to the doctor and decided to take medication for ADD. This was due to a lot of persuasion by my wife.”

When reading through this informant’s entries I initially bypassed that statement. It wasn’t until I read similar accounts in the other two diaries that I noticed the similarities. In the case of the informant with dyslexia she was in grade school when her parents took her to get tested. She says:

“My parents took me to Sylvan Learning Center to get tested for a learning disability. When I was tested they discovered I had dyslexia. My family took the results to the school district. They set up an IEP for me; I was able to get pulled out of my regular classroom for math, writing and reading.”
Of course, in this situation the informant with dyslexia was a child so it was expected that she receive assistance from adults to assess her learning needs. The informant with hearing loss was given hearing aids as a child but she chose not to wear them. She writes:

“I was given hearing aids when I was seven, but I refused to wear them because all the kids at school would ask me what they were for or give me weird looks. As a kid, all I wanted was to fit in so I would lie to my parents and say I was wearing them when I wasn’t.”

Although she was a child she chose not to wear the hearing aids that the adults wanted her to. She wanted to appear as if she was just like the rest of the kids at school. When she got into high school she received more pressure to wear her hearing aids. She says:

“Finally my senior year of high school, my mom convinced me to try new hearing aids and I got some. It was amazing how advanced the hearing aid technology was in the span of 10 years. The first hearing aids I owned were really big and bulky and they were really noticeable. The new ones I got my senior year of high school were barely noticeable and the color blended with my hair. I was so amazed when I got new hearing aids, I heard many things for the first time such as; birds chirping and soda fizzing. I was really surprised at all the sounds I was missing out on!”

Again, she had pressure from a loved one to obtain hearing aids. This time she chose to wear them and was amazed at all that she had been missing out on. The pressure that these informants received from loved ones to gain help regarding their disabilities doesn’t seem to be negative. They seemed helpful and caring. They did not want their loved one’s disability to affect their experiences or spatial interactions anymore that it needed too. However, this further illustrates that society has constructed an image of how the body should be and one should do whatever they can to conform to those expectations whether they want to or not.

**Conclusion:**

In conclusion, with this study I hope to show my understanding of the role that geography plays in society. As well as illustrate the significance of human-environment relations. My
intention was to focus on a group that is often excluded from research. Within the literature
review there were articles that highlighted research done for individuals with visible disabilities
but few that specifically showcased the experiences of different invisible disabilities. The article
written by Edward Hall about learning disabilities related to my research in that I used an
informant who has dyslexia.37

Individuals with invisible disabilities keep quiet about their experiences and struggles
with spatial interactions. This study attempted to unveil what exactly it is that causes my
informants and me to do anything in our power to hide the effects of our disabilities. With that
being said it can be determined that society has constructed the concept of what it means to be
normal. There are expectations regarding normality in certain spaces and the interrelations in
these places are what cause my informants and me to have experiences of frustration and anxiety.
An individual with an invisible disability is going to spend more time being conscious of how
their body is perceived in those spaces and focus on appearing normal. Sometimes they failed to
do so and had to deal with the consequences but sometimes they successfully hid their struggles
or pain. Their loved ones were aware of the expectations that society has placed on normality of
the body and helped the informants try to achieve that in some way. The pressure from others as
well as an internal feeling to comply with societies constructed image of how the body should be
is what keeps our disabilities invisible and keeps our experiences hidden.

Inspiration for this study came from my own personal struggles with an invisible
disability. I noticed the lack of representation of these types of disabilities in research regarding
the body. Not only is it important to share personal reasons for conducting research in order to

37Edward Hall, "Social Geographies of Learning Disability: Narratives of Exclusion and Inclusion."
show personal connections to the field but disability geography is a subfield where the personal is valued. By including the autoethonography as a research method I added another perspective and was able to relate to my informants as they kept their own diaries as well. At times it was difficult to include myself in the research process but it was a necessary addition that provided another aspect to the data. Sarah Wall states, “Ultimately using self as subject is a way of acknowledging the self that was always there anyway and of exploring personal connections to our culture.” That was my intention with this study.

---


Bibliography


