“Documenting the Thoughts and Experiences of People With Disabilities”

A Thesis Submitted to the

University Honors Program

In Partial Fulfillment of the

Requirements of the Baccalaureate Degree

With Upper Division Honors

Department Of

Allied Health and Communicative Disorders

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May 2013
HONORS THESIS ABSTRACT
THEESIS SUBMISSION FORM

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THESIS TITLE: Documenting the Thoughts and Experiences of People With Disabilities

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ADVISOR'S DEPARTMENT: Allied Health & Communicative Disorders

DISCIPLINE: Rehabilitation Services

YEAR: 2013

PAGE LENGTH: 12

BIBLIOGRAPHY: Yes

ILLUSTRATED: No

PUBLISHED: No

LIST PUBLICATION: N/A
ABSTRACT

The purpose of my research was to document the thoughts and experiences of people with disabilities. I interviewed three Northern Illinois University students who have disabilities. Although many topics were discussed, the focus was their educational experiences, accommodations, and challenges they have faced along the way. These interviews will be used to provide support for multimedia efforts being developed to teach people about disability in college. The students I interviewed stressed several similar messages. Each one wanted to seen first as a person. They viewed themselves as “normal” and did not want to be defined by their disability. They focused more on what made their life special or challenging, not the disabilities they had. Like any person, they had stories about what inspired them in life as well as challenges they faced. My experience with this study helped re-emphasize the importance of White’s (2002) “golden rule” for working with people who have disabilities. That is, “do unto others as you want them to do unto you.” People should treat others as they wish to be treated. In summary, this project helped me develop a greater understanding of how disability is an experience, rather than a condition.
Documenting the Thoughts and Experiences of People With Disabilities

Having the opportunity to work on a capstone project that was related to my future career-field proved to be a rewarding experience. I interviewed three Northern Illinois University students with disabilities, which strengthened my confidence and skills towards working with this population. Hearing about personal experiences directly from people within this community gave me new insight, including, a deeper understanding for the “golden rule.”

When I considered options for my capstone, I never imagined that I would have the opportunity to be involved in something that would potentially reach people all over the country. A group of students and myself were given the task of interviewing fellow students and staff members with disabilities. These interviews serve as the precursor for videos that will eventually be published on the NIU website. The intention of this project is to share the personal stories of people with disabilities and encourage more understanding and compassion in the people who watch them.

The inspiration for these videos began with an idea from the “This I Believe” webpage (www.thisibelieve.org). The site is filled with videos, audio-recordings, and essays from people all over the country. The stories shared represent individuals from all walks of life. Commonly, people talk about an experience that impacted their life and how it taught them something valuable. As a whole, this concept serves a greater purpose for those who take advantage of it. The executive producer, Dan Gediman, explains it as, “The goal is not to persuade Americans to agree on the same beliefs. Rather, the hope is to encourage people to begin the much more difficult task of developing
respect for beliefs different from their own" (This I Believe, Inc. 2013). This concept is an example of what the video project is meant to accomplish. As Mr. Giedman points out, hearing about personal experiences can encourage people to respect the different belief systems of others.

I began my project by contacting students I know that have disabilities to ask if they would be interested in an interview. Although I had specific questions in mind, I allowed each student to guide the conversation with topics that they felt comfortable talking about. Education, accommodations, and challenges associated with their disability were topics discussed. Although the meetings were confidential, I did ask each student if I could audiotape our conversations. This was helpful, as it allowed me to stay more engaged during the interview process. In the following paragraphs, I will describe my interviews and conclude with a summary of what this project meant. False names will be used to protect the confidentiality of the students who were interviewed.

"Patty"

The first person I interviewed, Patty, had a visual impairment. She developed a brain tumor when she was young, which was removed, but caused permanent damage to her eyes. Patty has ten percent vision in her left eye and no vision in her right eye. Being a person with less sight, she finds that certain tasks take her longer to complete, but she does not let it influence her goals. One of Patty’s most important goals was to attend college. Her experience at NIU began with a tour that included an explanation of accommodations for students with disabilities. Once she began attending NIU, Patty took advantage of the services that were available to her. She requested that her tests be made
with larger font, and she was given extra time to complete them. She also sometimes
found it helpful to use note-takers for some of her classes. She explained that even with
the use of her telescope, she usually could not see the projection screen. These services
were important for Patty’s success. Patty believes that when given the proper resources,
she can accomplish anything she puts her mind to.

Being a student at NIU has taught Patty a lot. She said, “a lot of people have said
that they are really proud of me for pursuing a college degree, but for me, I am just doing
what I think is important.” She explained how most things take her a lot longer to do, and
at times, seem much harder in comparison to other students, but she does it anyway. Like
any person, Patty wants to make her dreams come true. When asked about what is most
important in life, Patty said that she focuses on creating happiness, getting an education,
and spending time with her family and friends.

Patty also shared an example of a challenge that she faced as a person with a
visual impairment. She mentioned the week that NIU called for a snow day, and how that
was particularly a difficult time for her. The morning after one of the big snow events,
Patty knew that some of the paths would not be plowed. As she walked out of her
dormitory, she began to instantly develop anxiety. She looked around campus and
everything she could see was covered in white snow. This scared Patty. For her, it is
essential that she is able to see the paths to safely walk to her classes. Patty was
embarrassed to admit that, on one occasion, she almost walked into the stream that runs
along campus.
Susan was born with an umbilical cord wrapped around her neck, which temporarily cut off the oxygen to her brain. As a child, she experienced problems with her fine motor skills, which doctors believed were due to the complications during her birth. Susan was initially placed in special education classes because of her fine motor difficulties. Later, she returned to general education classes with a teacher’s assistant. Looking back, she stated that this was not the best option for her. She recalls feeling behind in class. The special education classes did not prepare her for the mainstreamed classes. She also felt uncomfortable using a teacher’s assistant. Having someone in class with her all the time made her feel embarrassed and different from the other children.

As a young adult, Susan questions if being placed in special education classes was a reasonable outcome for someone with a fine motor impairment. Her fine motor condition had no affect on her cognitive capabilities. Instead, the school could have provided an aide for her in the general curriculum. This would have prevented Susan from lagging behind in her academic subjects and helped her overall confidence. Most importantly, Susan only wanted to be treated fairly and as a person. She did not want to be judged based solely on her disability.

Susan currently has anxiety, depression, and obsessive-compulsive disorder. She found it hard to describe her conditions, so she tried to explain how they make her feel each day. Susan said that she experiences anxiety throughout the whole day and that she often finds it difficult to get out of bed. She explained it as if only half of her wants to do the everyday activities of life, and the other half of her does not want to do anything at all. She said, “I used to be a lot more depressed, but as I get older my anxiety is getting a
lot worse. It’s like; the more I feel the more anxiety I have. So, I feel more, which is good, I guess, but I have more anxiety.”

Susan’s sister, Kelly, has inspired her to work with people with disabilities. Kelly has autism and while caring for her, Susan has developed a strong desire to work with children who have special needs. Susan reflected on what began her journey in wanting to help people. She was at the grocery store with her sister, and Kelly was having a bad day. She was throwing a tantrum and being quite loud. Susan felt appalled by the reactions from people in the store. She said, “I will never forget the looks that people gave us, how inappropriate!” This situation made Susan feel frustrated and she also felt bad for her sister.

“Terry”

Terry was diagnosed with Bipolar disorder. In High school, she struggled with issues related to her home-life and her friends at school. She especially found it difficult to break up with her first love. At the time, she thought her boyfriend was the most important part of her life, and when they separated, she fell apart. Terry felt so depressed that she committed herself to a mental health facility. She often felt hopeless and did not care if she lived or died. She became scared to be alone because she thought she might hurt herself. Terry knew that her feelings were too intense, but the medication that she was given wasn’t helping her much.

Now, a sophomore at NIU, Terry finally feels like she has her life in control. She feels more content with her medication, and she knows that it helps to make her daily life more manageable. She still struggles with extreme highs and lows, but she works through
it, especially with the support of her peers. Terry said that she does struggle with the college experience at times, but she uses the resources available at NIU to help her cope with being a student. She mentioned that Shelia Milan, coordinator of the Disability Resource Center (D.R.C.), made her feel special. Shelia focused on her strengths and pointed out how well Terry was doing in her classes. Shelia gave Terry encouragement and motivation to continue working, despite the challenges she faced. This positive experience inspired Terry to be more proactive. She was so grateful for Shelia's encouragement that she decided to give back. At the time, the CAAR office (now D.R.C.) allowed students receiving services to assist in introducing new students to NIU. Terry enjoyed helping other students. It made her feel good to provide information and encouragement, similar to what she had received.

Terry also mentioned that due to her disability, she was able to use the testing center. The testing center allows for a quiet environment and provides most students with additional time for testing. Terry was excited about the prospect of using this service because she found it difficult to take tests with any type of background noise. Unfortunately, this accommodation was of little help to her. When Terry visited the testing center, there were always a lot of students there, and the noise level seemed similar to what she experienced in the classroom. She said that it was especially bad during finals week. Overall, she feels that a room with no more than three to four students would be more beneficial.
Summary

This project is important on several levels. Societally, the multimedia to be created from these interviews may influence people to view disability from a different perspective. People who eventually watch these videos will find that they can relate to many of the experiences that were shared by students with disabilities. In fact, during the majority of my interviews, the students focused more on what made their life special or challenging, not the disabilities they had. Like any person, they had stories about what inspired them in life as well as challenges they faced.

Hearing directly from someone with a disability creates a special connection between people. I believe it nurtures our ability to respect the differences of the people around us. Everyone has goals, values, and personal beliefs that guide their life. Our physical, sensory, and mental abilities are but one aspect of what makes us human. My experience with this study helped re-emphasize the importance of White’s (2002) “golden rule” for working with people who have disabilities. That is, “do unto others as you want them to do unto you.” People should treat others as they wish to be treated. People often know that they should act this way but may not know how to demonstrate it, especially with people from other backgrounds. Before my experience with the interviews, I wanted to treat people with disabilities with respect but I am not sure that I would of confidently been able to do so. I believed in the concept, but I did not have enough personal experiences to understand people within this population. Following this experience, I have much more confidence in my ability to talk with a variety of people who may have disabilities.
As expected, the students I interviewed all had unique experiences and beliefs. They talked about their life and what had impacted it. They felt that their disability was just one part of the whole picture that made up their life. Of course, their disability influenced their life but it did not define them and they did not want to be labeled in that way. As the golden rule implies, these students only want to be treated like everyone else.

This project helped me develop a greater understanding of how disability is an experience, rather than a condition. These interviews helped me truly see each individual for who they are, rather than thinking about them in terms of their disability. I realized that no matter what challenges someone might face, their experiences and personality influence their daily life the most, not their disability. I was also able to learn more about different kind of disabilities, and what it means for an individual on a daily basis.

Understanding different perspectives of disability directly from people who have them was one of the best experiences I have had at NIU. Learning about disability through academia is helpful, but hearing about it from someone who lives with it is a completely different learning experience. When reflecting upon my conversation with Patty, for example, I learned so much about what having a visual impairment might feel like. She helped me understand what it is like to live with vision loss on a daily basis, which is something that you cannot learn about in a book or a class. Hearing about her goals and beliefs helped me see her as a person, not as someone with a disability; and understanding more about her daily life helped me to develop more compassion and respect for people who have disabilities.
References


This I Believe, Inc. (2005) *About This I Believe*. Retrieved from: http://thisibelieve.org/about/