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## The Truth Behind Individuals with Disabilities: Interviews of Students and Faculty Members

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**NORTHERN ILLINOIS UNIVERSITY**  
**The Truth Behind Individuals With Disabilities:**  
**Interviews of Students and Faculty Members**  
**A Thesis Submitted to the**  
**University Honors Program**  
**In Partial Fulfillment of the**  
**Requirements of the Baccalaureate Degree**  
**With Upper Division Honors**  
**Pre-Physical Therapy**  
**By**  
**Broc Pagni**  
**DeKalb, Illinois**  
**December 2013**

## University Honors Program

## Capstone Approval Page

Capstone Title

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“ The Truth Behind Individuals with Disabilities ”

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Student Name  Broc Pagni Faculty Supervisor  Dr. Greg Long 

Faculty Approval Signature \_\_\_\_\_

Department of  Allied Health and Communicative Disorders Date of Approval  May 3, 2013

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## Abstract

The main goals of this study were to gain the insights and perspectives of NIU students with disabilities as well as increase my comfort and knowledge about this population. Information gained from this study will be subsequently shared and incorporated into several multimedia projects being developed by my capstone advisor, Dr. Greg Long. Although data was obtained from interacting with students with disabilities across several different settings, the primary data for this study came from three interviews held with NIU students. Gaining the perspectives of people with disabilities benefitted not only myself, but also benefitted the interviewees who shared. This opportunity gave people with disabilities a forum to share their thoughts and perspectives. Throughout the process I was able to receive advice on how people with disabilities like to be treated, what barriers and struggles they have faced, and what characteristics and qualities make an excellent or poor health care provider. The interviews have allowed for personal growth and experience working and interacting with people with disabilities, contributing to increased comfort levels. A qualitative research methodology was used. A skeletal outline of interview questions was used to stay focused and cover important topics.

## **The Truth Behind Individuals With Disabilities: Interviews of Students and Faculty Members**

An estimated 48.9 million people in the US who are not incarcerated have a disability according to a U.S. Census Bureau Survey. This is roughly 20% of the population ranging from learning, physical, mental, and invisible disabilities. Society is generally lacking knowledge, awareness, and comfort regarding disability. The purpose of this paper is to bring education and awareness to society about people with disabilities. The lack of knowledge can be particularly problematic at college for students with disabilities. Transitioning to college life can be challenging with rules for accommodations changing. Additionally, most faculty and staff have minimal background and training when it comes to working with these students. People with disabilities experience a degree of judgment, stigmatization, and discrimination throughout some point of their life. Therefore, this project was designed to gain perspectives and experiences of a sample of college students with disabilities. The importance of addressing the lack of knowledge about this topic is essential to move toward a more cooperative and understanding society. The knowledge gained from this study will be used to supplement multimedia training projects being designed by Professor Long. By conducting interviews of people with disabilities, I was able to interact and hone

my etiquette skills learned in the classroom. This experience will prove beneficial in my field of Physical Therapy. I hoped to gain insight on the perspectives of people with disabilities when working on this project. I also hoped to learn how to act natural and calm in a setting that may promote anxiety and tenseness. As the interview process progressed, I had made drastic progress and made improvement in all aspects as a future Health and Human Service provider. The testimony of those who were interviewed was motivating and inspiring.

By conducting interviews with people with disabilities, we are able to share their story with the public and gain experience working with these individuals. The interviews gave individuals a chance to share their personal experience and provide life-changing lessons. People without disabilities will have a chance to see what individuals with disabilities experience on an everyday basis. This will bring insight to what truly matters in the eyes of those with disabilities. People often act biased and overly judgmental toward people with disabilities so it is highly important to educate the public. The interview process has provided a hands on learning experience as I worked with people with disabilities and furthered my personal skills. The interviews covered a range of different topics that will prove beneficial to all people.

## **Methodology**

### **Participants**

For this study, three individuals were interviewed. One was an undergraduate student, the second was a graduate student, and the third was a faculty member. All participants are associated with Northern Illinois University. They included:

- 24-year-old Caucasian male who is legally deaf in both ears.
- 18-year-old Hispanic female who has Fanconi Bickel Syndrome.
- 32-year-old Caucasian male who is paralyzed (cervical 7 lesion) from the chest down.

### **Instrument**

An outline was composed to serve as guidance from question to question. The outline was an aide to keep focused on important topics and to solidify that no topic would be missed. Topics included school-related questions, societal attitudes and responses, and family-related questions. Most questions had multiple parts and depended on the response of the previous questions.

## **Procedure**

The interview process began by gathering individuals with disabilities who were willing to share their story. As a professor in Disability in Society, Dr. Long was able to recruit interviewees from the classroom. Colleagues and I were also able to gather students, faculty, and staff with disabilities on campus. Our study group encompassed individuals with disabilities who were willing to discuss their life experiences openly. These individuals were contacted via email and meetings were held in a setting of their choosing. I obtained consent of participation from all interviewees. Each participant signed an “Unlimited Release Form” giving permission to be interviewed and recorded. The interviewees encompassed a multitude of disabilities and disorders. This wide-ranged interview group ensured a variety of lessons from people with disabilities. The interviews ranged from 15 minutes to 35 minutes in length.

## **Results**

Because this study used a small sample, each participant’s interview will be described separately. Each participant discussed different topics that were of particular interest to them. Testimony covered includes direct quotes from the participants.

## Michelle Space

When first meeting Michelle I noticed her short stature. I initially thought she was a dwarf but there was much more to it. When asked to share about her disability/disease, I learned Michelle's disease affects her kidneys, liver, and bones. Her kidneys bring about genetic dysfunction and require her to take a lot of medicine. She has to be cognitive of what she does, what she wears, and how she walks especially in winter. This was an eye-opener because at first glance it didn't seem like she had any health issues. She seemed like she was healthy. Michelle faces a lot more adversity than what most would think. She has to be on a diabetic diet and has to monitor all food and drink intake.

When asked what she has learned through her disability and society she replied, "I am just like everyone else". She does the same things as everyone else, just in a different way. This is an important part of the interview because it shows that she considers herself no different than anyone else because of the route she may have to take to do something. There is no right way to do anything but there may be a common way that most do things. Michelle would not change anything that has happened to her. It has all made her who she is today and it has brought her down a road where she has met so many people. Her experience made her into who she is today. This agrees with the general statement that most people with disabilities would not take a "magic pill" to cure their disability. Michelle would

however be willing to take a pill that took her health problems away, but not one that made her not as short and small.

Michelle also discussed her transition to NIU. In high school everyone knew her as the girl in the wheelchair. Upon coming here, she was able to separate herself from that degrading label. She has found the residence halls extremely accommodating and has had no accessibility issues. Staff members have lowered her bed and adjusted several other things for her.

Michelle also talked about the accommodations that she has in the classroom setting. She is allowed more absent days because she becomes ill often. She has priority seating and registration but she stated that she tries not to use them. Instead of using the system to benefit her, she instead try's to break away from it just so she can be like anyone else. This shows that she doesn't want to be treated differently. I asked Michelle if she felt offended when people ask about her disability when they first meet her. She actually prefers that people ask her as long as they do it politely. Michelle wants people to ask her because it brings them closer to acceptance and understanding.

## Jim Carter

When asked to talk a little about himself at the beginning of the interview, I found out how involved Jim Carter was within his community. Jim had left no opportunity on the table and took complete advantage of the services on campus. He used the acronym “YOLO” to describe his outlook on life. “YOLO” stands for You Only Live Once. Jim wants to take advantage of his time here and make the best of it. He said that “if you don’t go out and do anything, people won’t remember you”. Mr. Carter is 99% deaf and said that he basically doesn’t hear anything without his hearing aide. With his hearing aide he is able to hear up to 50%. Jim said his disorder has taught him to never give up. He has learned to never let it bother or discourage him. People may think that he has a problem, but he doesn’t think of it that way at all. Those that think he has a problem are the ones who really have a problem. This can bring perspective to those who are less accepting of those with disabilities.

Jim was asked to talk about his school experiences. When he was in high school he was in the mainstream classroom. Students didn’t treat him like they treated everyone else. Jim quit activities he was involved in just because of poor treatment from others. When Mr. Carter attended a community college his school day consisted of driving there, going straight to class, and then leaving. There was no involvement when he was there. But when Jim came to NIU, he had a different

approach to school. He pushed himself into the community and got involved. Those on campus liked Jim for who he was and saw his personality. When assigned group work, he stated some students became uneasy working with him. He said that he would jump straight in and start interacting. This was extremely motivating. For someone who has felt such separation and disconnection from students around him, Jim did not let any of that bother him. He did not let the attitudes or behaviors of others slow him down from what he felt like he was accountable for. Jim's proactive behavior brought transformational perspective to those who he interacted with. Jim Carter was going to do whatever he set out to do and nobody would stop him. Although Jim may have felt the same feelings early in his experience, the restraints and barriers have been slowly torn down and Jim now lives life to the fullest.

When asked what he would suggest to others with disabilities, Jim responded by saying he would tell them not to back down. He suggested the Disability Resource Center and said marvelous things about the interpreters. He also said "do not hesitate to ask for accommodations." These wise words provide direction for incoming students with disabilities who are about to begin their college experience. Jim said he would like people to interact with him just as they would anyone else. Jim's biggest barriers are talking to people on the phone. At times, he has to have people call for him and he doesn't really like that because it

puts him down. He prefers to use text messaging and email. Also, there are a lot of employers that he has experience with that were worried about him failing at the task. Jim could perform any task just as well, if not better, than most but because he is deaf his employer underestimated his ability.

Jim Carter talked about how he was exceptionally competent at reading body language. He notices the exact moment that someone figures out he is deaf just based on their body language. Jim isn't able to understand someone when they turn their head away from him. He needs to watch their facial expressions and the movement of their lips. This is extremely important to know for anyone interacting or working with individuals who are deaf. Jim communicates best through American Sign Language (ASL) because that was his first language. He said that ASL goes well with emotions and he really loves the way that you are able to communicate on a different level. The biggest downfall of being most fluent in ASL is that very few people know how to sign. Jim has had to overcome adversity and accept that he will only use ASL with the few in his life that know how to sign. Jim also picks up on music from the vibrations and beats. He says he likes rock and heavy metal music because he can follow along. Music without beats and vibrations are difficult to understand and he doesn't enjoy it.

“Do not judge a book by its cover” was Mr. Carters' reply when asked the question “What is one message you would like to share with the world?”. You

have to get to know a person before you can place judgment on the individual. This was Jim's message that he would like to share with the world.

## Steve Maker

Steve believes the most important things in life are the relationships you establish with people. Family and friends are extremely important to him. Steve sustained a C5, C6, C7 spinal cord injury after a fall in January of 2002 leaving him paralyzed from the chest down. Steve is classified as an ASIA 8 complete. Steve said that his injury has taught him that he needs to be more accepting of society and of himself. He said that it took a long time for him to accept his disability. Prior to his injury, Steve was an athlete and was a part of the football team.

Steve used the Disability Resource Center (DRC) for accommodations at Northern Illinois University. Once he became accustomed to the services he realized he didn't need all of the accommodations that he was given. Steve believes people use their disability as a crutch and abuse services that are not needed. He recommends using only the services that you need. Steve has learned to navigate buildings as effectively as possible with his wheel chair. Older buildings are especially difficult for him. It is also a challenge during winter with snow and

ice not being the optimal travel conditions. There are also barriers in the community. Steve is from Rochelle and DeKalb which have a lot of old architecture which make it hard to maneuver. It is definitely a continuous struggle getting around places that are not wheel-chair friendly.

One of Steve's biggest barriers is slow reaction times to accommodation requests in buildings, especially at universities which can sometimes be a bureaucratic nightmare. He has been pushing for an accessible door way accommodation for 8 years now and it's not that they don't want to help, but they get bogged down in the minutia of the details. It is finally looking like he may receive the accommodation he has been pushing for. There are many barriers to access and functional usability. Steve has repeatedly requested accommodations with table height in Davis Hall but had never seen any changes occur. Some professors of the university and staff of the CARR department ignored his request. The department never told him no, but they would always say that they were working on it but nothing ever happened. Steve is not fond of these leaders and feels his effort to help initiate accessibility around campus has been wasted. Steve has heard through the grape vine that adjustable desks had been ordered for just Davis Hall so his investment may not have been in vain. Aside from bad experiences, Steve has also had good experiences. Two weeks after requesting an

accessible door for Davis Hall, Steve was more than happy to see that the door was installed.

Steve said he has never been treated with less than respect because of his disability. When the injury initially happened, his friends were awkward because they didn't know how to react. Some friends were ice breakers. Humor has been a big part of his recovery. Through making fun of himself, Steve has learned to accept who he is. Steve believes that most people by in large don't do anything to stifle or inhibit him. His experience with healthcare professionals has been both good and bad. When Steve was first injured, some of the experiences he had with the Certified Nurse Assistants (CNAs) were awful because of the level of response and quality of care. Steve said, "I found it typically to be the laziness of the person and their knowledge. They would cut corners...one time they went to move me from the bed to the wheelchair and the nurse forgot to lock down the wheels and the bed started moving, almost landing me on the floor. She did nothing to help and thankfully my brother was able to assist the transfer." Steve stated that he has also had wonderful experiences with CNAs. He liked when they took the time to explain things to him and those that were patient when trying to do something with him. The ones that forged relationships really stick out in his mind. His advice to future healthcare providers is to just listen to the patients. Actually take the time to listen to what they have to say. Just because you may have training in a specific

field does not mean you understand the extent or severity of their injury. It is easy to quickly give a remedy to a patient but often times if you take the time to better understand what is going on with your patient, you are more likely to get to the root of the problem.

Steve Maker wants to be interacted with just like anyone else. He doesn't want special treatment and wants to feel like a normal member of society. Steve encourages students to prove people wrong about their capability to complete tasks. Show them that you are willing to go above and beyond. When someone meets a person with a disability it is natural tendency to immediately think there is a limitation. It's important to show them that you are fully capable. Steve hates the term cripple. He doesn't worry about person-first language so much and said that his family often didn't use it because of a lack of education and ignorance. Steve likes the idea of person-first language but he isn't offended by the absence of it.

When asked if he would take a magic pill to remove his disability, he said it depends. He replied with, "If you were saying a magic pill that would reverse time and go back to the day I got hurt, and I wouldn't get hurt and everything would go on normal from there, I would say no because a lot of good has come from my disability. A lot of my personal experiences have come from my disability along with a lot of frustration and things I care to forget and never have to do again but my brother and wife got together when I got hurt. They now have four children

that I love dearly. If a magic pill meant going back in time and changing everything, I wouldn't do it. If it meant I could take a magic pill today and be able to walk again, absolutely in a heartbeat one hundred percent. I would like to be that active person who doesn't have any barriers and can walk around, and be able-bodied".

One message Steve Maker would like to share with the world is to keep an open mind. Be prepared for someone like him to blow you away if you set the bar too low. Many people like himself, aim not to meet expectation of able-bodied people, but aim to surpass them and excel. They are often willing to go above and beyond. Steve believes his family deals with a lot of frustration because of his disability. They are not frustrated with him; they are frustrated with the challenges he has to face. Steve said a lot of times they take it harder than he does. "If my mother knows I have a bad day she is in agony she doesn't want to see me hurt or anything." When Steve was first injured, it was hard for his family and him to understand his limitations. Often his brother and parents would expect more of him than he was able or they would think he was using his injury as an excuse to be lazy. Now however, Steve and his family are comfortable with his limitations.

## Conclusion

Throughout the interviews, countless emotions surfaced as they told their story. When I first met Michelle I was shocked to hear she had as many health problems as she did. It is easy to assume what life with a disability would be like but until you experience it, it's impossible to truly understand the difficulties they face on an everyday basis. Luckily, Michelle blessed me with the opportunity to get an inside look into her life. When I first met Jim I was amazed how involved he was within his community. Listening to Jim's philosophy and approach to real world scenarios was inspiring. I feel like many refrain from taking action and saying what's on their minds for the sole reason that they are worried what others may think of them. Jim is willing to verbalize and communicate through whatever method suitable to explain what is on his mind. When Jim spoke of ASL being his optimal way of communicating, it sparked curiosity. From my perspective, the thought of not being able to communicate in my native language sounds at times suffocating. When Jim meets someone who signs, I am sure there is a strong connection between them. I imagine he feels at home and appreciates that he is able to communicate in the most pleasurable and passionate form. When Steve Maker said that he wouldn't take a magic pill because his brother and wife met through his injury I was astonished. Steve selflessly would experience the pain and struggles that he's faced since he was 16 years old just so his brother can meet his

wife. Steve's love for his family became evident to me. Hearing the three individuals' testimony revolutionized my current philosophy of life.

By educating the public we can transform the perspectives of people with disabilities and increase the level of acceptance in order to create a more cooperative and productive society in the future. This topic is of great importance to me because I believe it is my job to help educate the public to manifest a more acceptable and healthy outlook on life for future generations to come. Future students will have the opportunity to build off what I have learned. The results compiled from colleagues and I will be passed on to Dr. Long, faculty members and students to assist in the creation of short video clips accessible to all. This learning experience has brought transformation to my overall outlook of persons with disabilities and the best way to live life. The stories of the individuals interviewed have benefitted my own outlook on life. Throughout my trials, I have become more relaxed when placed in potentially uneasy situations. I have been able to practice respectable behaviors and common courtesy that I have learned in the class room setting. I have also learned to interact with individuals with disabilities appropriately and have become comfortable asking questions without being offensive.

The participants seemed to enjoy the interviews and were curious how their stories were going impact the community. Some questions that were asked had

never been thought about by the participants and required beneficial exploration in their thoughts and views. The participants appreciated helping a fellow student and contributing to a larger product designed to help educate others. A limitation of this study was the small sample size. The population interviewed was from the same community and institution (Northern Illinois University). The variation of ages, genders, races, and occupations was also limiting. Our world is in dire need of a paradigm shift toward a generation willing to be receptive toward the needs of those with disabilities. These interviews will serve as a stepping stone to this paradigm shift. The world will then have access to dive inside the life of individuals with a multitude of different disabilities.

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