

Spring 5-4-2015

A Deeper Look

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Repository Citation

Spicer, Jessica, "A Deeper Look" (2015). *Honors Projects*. 180.
<https://scholarworks.bgsu.edu/honorsprojects/180>

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A Deeper Look

Jessica Spicer

Honors Project

Spring 2015

As I thought about what I wanted to do for my Honors Project, I knew it had to be something that I was passionate about and that would make me feel like I had accomplished something when it was complete. There are a group of people that I work with when I am home for the summer, and my true love for this group of people have helped me to decide my career path. I have had the privilege to work with people with cognitive and physical disabilities through my county board of developmental disabilities. I realized through my work however, that there are many people who very seldom if ever come into contact with people with disabilities. I therefore decided to use my Honors Project to introduce this group of people to you, and most of all to show everyone that they are exactly like any of the rest of us. They have the same hopes and dreams that we all do. They have struggles and successes. They have the need to be loved and enter into the same type of relationships that we all do. They have joy and they have sorrow. They have histories that have shaped their lives, and they want people to get to know them for who they are on the inside, not just how they appear on the outside.

I interviewed a group of people that are served by the county board of developmental disabilities and asked them all the same questions. These questions include:

- 1) What do you remember about your childhood?
- 2) What has been the happiest moment of your life?
- 3) What has been the most difficult part of your life?
- 4) What are your dreams for the future?
- 5) What do you want people to know about you?

Hopefully the answers to these questions will help to show that people with disabilities are no different than any of the rest of us, and in fact we can learn a great deal from them if we take the time to do so.

Please understand that I have asked these questions to a group that have a large range in cognitive abilities, some with limited verbal skills. I have been given the blessing by all of them to put their answers into words that are easier to understand on the printed page, without changing the content of their answers. Also, due to everyone's basic need and right for privacy, I will identify each person by a letter only.

Along with their personal information, I have also added in some factual information along the way (displayed by three asterisks), to help further explain their answers or the impact of the information that they are sharing. I hope that I am able to show you what an amazing group of people they are and that in the future, you will look at them with the same amount of respect that I already have for them. Statements in brackets are personal opinion/ known facts of the author based on previous experience.

Person A:

I am 76 years old, so I have lived a long time, and lived through a time when people with disabilities were treated very badly. According to what people told me, I was placed in Orient State Institution shortly after birth. My time at Orient was definitely the worst time in my life.

*** (It was very common in the not so recent past, that if an infant was born with an obvious disability, that the parents were encouraged to place the child in an institution, and that is often where that person would live out their life. Orient State Institution was established in 1898. It was actually at one point called The Asylum for the Education of the Idiotic and Imbecile Youth. And then the name was changed to Institute for Feeble-Minded Youth, before it finally simply became Orient State Institution. It is well known now, that the abuse that people suffered at Orient is indescribable. Physical and sexual abuse was the norm. People were chained to walls and not fed for days. It must be understood that there was a time that people with disabilities were thought of more as animals than humans. Orient was closed in 2002 and converted to a prison. It is said that it needed extensive updating to be appropriate to become a prison, so that speaks to how horrible the conditions were)*** (Safford & Safford, 1996)

When Orient closed, I got to move to a place in Fairfield that was much better. The happiest time for me however, was when with the help of my guardian; I was able to move into a home in the community. It was an actual house with my own things. Staff took care of me during the day and I got to go to a program where I got to do things during the day that I like. I love to sing and Barry Manilow is my favorite!

My dreams for the future are just to life out my life in my house where no one hurts me, and I can do what I want, and what I want people to know about me is that I am very strong and brave because I survived a life that most people can't even imagine.

Person B:

I am a 35-year-old man, and I just love everybody!! I lived with my family as a child, but they didn't treat me very well. I am autistic so I have a lot of energy and sometimes I get really mad and I will hit myself. The rest of my family didn't really know how to take care of me because they have a lot of problems.

[It was very common in the past, especially in the area where there is a large Appalachian population, that family member including cousins and even brothers and sisters would marry each other and have children. In the United States, while incest is not statistically high, certain regions suffer from quadruple the rate of incest (Lapidus, 2011); such as many of those from the poverty-alcoholism stricken region of the Appalachian Mountains and the swamps or backwoods of the Deep South. These parents would also often times have their own disabilities or mental illness, so it was not uncommon that the children would often have disabilities.]

I had to go to the hospital when I was a teenager and that is when everyone found out that I had been locked in my room in a trailer for years. I was removed from my home and put in a nursing home. That was terrible, because I was a teenager, and I didn't like the nursing home. I was then put in an ICF in Fairfield.

(An ICF is an Intermediate Care Facility, and these were built as State Institutions were closed, and they were supposed to be a better option for people who still needed institutional type care. They were better, but still not the perfect situation for a lot of people. They still exist, but now they are built with individual cottage type homes so the people who live in them feel like they live in a more normal home like setting.)* (Safford and Safford, 1996)

I got to start going to school then, and it just so happens that I am really smart. I learned to both read and write. I am great at Wheel of Fortune! The happiest time of my life was when my guardian [who just so happens to be the author's mom] helped me move to a community home. I have 5 other roommates who keep my company. I get to go to a Day program where I get to play on the computer. I love to type numbers and letters. I want my future to be just like things are right now. I like my house and I love everyone. I want people to know how smart I am even though if you meet me, I may just repeat the same thing over and over again.

Person C:

I am a 42-year-old woman who lived with my family growing up. It was the worst part of my life because I was physically and sexually abused.

(Statistics show that people with disabilities have a very high percentage of being sexually abused. As many as 83% of women and 32% of men with developmental disabilities have been thought to have been sexually abused, and it is probably much higher as abuse of people with disabilities is often times not reported.) (Baladerian, 2012)

I was able with the help of the county board get a house in the community. At first I had a hard time because I also have mental illness.

(It is not uncommon for someone with DD to also have mental illness. It is thought that as many as 10-40% of people with DD also have some type of mental illness) (Baladerian, 2012)

I acted out a lot because of my history, and I had to have a lot of staff help. I have done so well now that I can live in my home for much of the day by myself with no staff. I have a boyfriend and we get along really well.

[It is perfectly normal for people with disabilities to be involved in relationships, including the physical aspects of a relationship].

This is the happiest that I have been so far in my life. I would like to get married some day and live on my own. I want people to know that I am just like them.

Person D:

I am a 34-year-old man, and I lived with my family growing up, and I was treated very badly. Members of my own family sexually abused me and I was neglected. I now live in a community home with staff, and I have a full time job in the community. I have a girlfriend and lots of friends. Life right now is the best it's ever been. I want to keep working and making money so I can do things that I like to do. I want people to know that when you see me in public, talk to me. I like to tell you about myself and I love to talk about sports. I may talk a little slow, but if you are patient, you will find out that I am very interesting and I know everything about high school football.

Person E:

I am a 53-year-old woman who grew up with my family and it was very good. It was the most favorite time of my life. I love my family. We lived on a farm, and I had a brother. One of the worst parts of my life though was when my brother had a tractor accident and he was hurt very bad. He had a brain injury, and DD took care of him too after that.

[People are considered eligible for Developmental Disabilities services through the county board if there disability was present before the age of 22. You do not have to be born with it. Many people being served by DD may have a traumatic brain injury before the age of 22 and are now being helped. They could have lived the beginning of their lives as a person without a disability].

Everyone took good care of me. I have Down Syndrome so I need some extra help, but I can do a lot of things. I lived in a house with one roommate that I had lived with for years, but she died last year. That was another bad time of my life. I still miss her very much. She had Down Syndrome too. I work at McDonalds and I am very proud of myself for that. I make a lot of money and I like to save it. I like to have a boyfriend, but they have to treat me just right, or I will get rid of them. I want people to know that I can do all the things they can do and I have the same feelings that they do. I am sad just like they are if something bad happens to someone I love.

Person F:

I am a 56-year-old man and I grew up with my family. My mom took very good care of me. She is in a nursing home now, but I still get to see her and being with her was my favorite time. I live in a community home now and I like it. My favorite things to talk about are cars and going to work at the car shop. [He has never worked but that's OK because he sure does love to talk about it anyway!] I go to a Day program during the day and I like to be with my friends and I like to do art. The day program actually has an art studio, where people with disabilities can do all types of art and then sell it. My hometown actually had a contest where people could contribute art and the two best works of art were placed as large murals in the center of town. One of the winners was a person with disabilities. The judging committee did not know that she had disabilities when her art was chosen. The worst time in my life was when I fell and had to go to a nursing home for a long time. The only good thing was that they let me stay at the same nursing home that my mom is at so I got to see her every day. I want everyone to know that I love my brother very much, and I love cars!

Person G:

I am an 82-year-old man who has lived on my own in the community all of my adult life.

(This individual probably could have used more help than he received, but DD services are voluntary, so sometimes all we they do is what people allow)

It hasn't always been easy. I have been hit by a car more than once crossing the street, but being on my own is very important to me. I worked in a sheltered workshop for as long as I can remember. I make a paycheck and that is the most important thing to me. I have a lady in my building who will check in on my, but I can do everything on my own and that is what makes me the happiest. People need to know that a lot of us can do everything on our own. I can't really think of any part of my life that has been bad.

Person H:

I am a young man in my 20's and my life now is great, but it hasn't always been that way. When I lived with my mom, her and I were both abused by her boyfriend. It got so bad that my mom killed him and didn't tell anyone for a few weeks, and his body was in our bathtub. I was taken out of that house when they finally came in and found him. That was the worst time in my life. Now I live in an apartment with my girlfriend, and I work at a regular community job and make a good paycheck. I have learned to be responsible and do lots of things on my own. I still have staff that helps me with things like going to the Dr., but otherwise I am independent. I have learned that life doesn't always have to stay bad, and other people need to remember the same thing.

Person I:

I am a young man who lived with my family for a while, but as I got more difficult to take care of, I was put into an ICF. I missed my family a lot but they did come to visit me. I didn't like the ICF because I like a lot of attention and there were too many other people there for me to get that. Luckily my guardian worked hard so I could get out of the ICF and get a community home.

[A few years back the state of Ohio released money called Martin Waivers to help get people out of nursing homes, and ICF's and into community homes.]

I was so happy when I got a house. I have two roommates my same age, and we get along really good. My favorite things are my meetings. I love to have meetings about me, and I like to invite lots of people so they can all talk about me in my meetings.

Person J:

I am a woman in my early 40's with Down Syndrome. I lived with my parents until they got old and passed away. My brother took me to live with him, but I don't think that he really wanted me there.

[This is not an uncommon situation. Parents make family members promise to take in a family member, and they are really not capable or willing to care for them]

I had someone that I really liked at workshop, but my brother didn't think that I should be allowed to have a boyfriend. I was called fat a lot, and I didn't get to eat very much. I didn't like living with my brother at all. Now I live in a community home and I am very happy. I want people to know that I should be allowed to do whatever I want just like anyone else.

Person K:

I am woman in my late 30's. I am in a wheelchair because I was in a car accident in my late teens. I got a bad head injury and so I need a lot of help. I do live in a home in the community, but my parents are very involved in my life. In fact, my dad is my legal guardian, so he makes sure I get what I need.

[Many people being served in the DD system have legal guardians appointed by probate court, when it is found that they are not capable of making decisions in their best interest. It is always preferable that a family member becomes guardian, but if that is not possible, there are actually agencies that serve as legal guardians.]

I remember what it was like to not be in a wheelchair and have all of my other problems, and that makes me very mad. I don't know if I will ever be able to let that go. My favorite thing to do is sit out in the sun. When summer comes, I could sit out in the sun all day. People should remember to treat people with disabilities well, because you never know if you will end up being a person with disabilities yourself.

Person L:

I am a young woman in my mid 30's. I have autism. I had my own home for a long time that my parents bought just for me to live in. I had staff all the time day and night. I am very lucky though that my parents had a vision, and luckily the means to make it come true. They bought a farm and built numerous small houses in it, and opened it up as a community for people with autism to come and live. We have lots of animals and a day program to go to. Everything we need is right here on the farm. We have staff in each house that helps take care of us. I don't talk a lot, but my smile should tell everyone that I am happy living here.

Person M:

I am a woman in my late 30's and I have Down Syndrome. So does my husband. Yes, you heard me right, I am married and my husband and myself both have Down Syndrome. We live in our own apartment, and we both work. Our family members do come in and check on us every once in a while, but we are really independent. My husband makes me very happy but sometimes he gets on my nerves. Sounds like pretty much any other marriage doesn't it? We have help if we need to work out a problem that we can't work out on our own. I want people to know that people with disabilities can get married just like anyone else.

Person N:

I am a 65-year-old woman. I lived my early life in Orient State Institution because that is just what parents did with kids that were slow back then. I got to move out and get a home eventually though. I have a very exciting part of my life to talk about though. I was in the movie Rain Man. It was really fun, but I don't like Tom Cruise. He wasn't very nice.

[There were actually numerous people that our county board serves that were in Rain Man. In the scenes that took place in the institution, many of the extras in the background, were actually people with disabilities]

Now I go to a day program, and when I get old enough and don't want to go, I can retire. I like to tell people that I am a movie star.

Person O:

I am a man in my late 60's, and I have lived in an institution all of my life, either Orient or an ICF. I was finally lucky to get a Martin Waiver and move into a home in the community. I have staff that helps me. I love Christmas. Every time the workshop where I was, put up the Christmas tree in the office, I would stop at the window and look at it and cry. It makes me so happy to see Christmas trees. My favorite thing to do is eat.

[It was not uncommon in institutions to have food withheld as a form of punishment, so many people who have lived in institutions will steal food, hoard food or just over eat, because they have never learned to understand that food will always be available to them now]

I am just so happy to finally be out of an institution.

Person P:

I am a woman in my 50's and I have CP. [Cerebral Palsy. It occurs when there is a lack of oxygen during birth] I have a lot of physical disabilities. My arms and legs have contractures, and I have a feeding tube that I get my food through. I have a lot of difficulty speaking because my muscles don't work very well. I own my own home and I have staff that helps me. I was more independent when I was younger but I have gotten weaker as I get older. The thing that people may not know about me is that I have completely normal intelligence. In fact, I am extremely intelligent. It is just that people see me in my wheelchair and they listen to me talk, and they assume that I have a cognitive disability. That is not the case. I am completely aware of everything that goes on around me and I understand everything that you say to me. It just takes me a long time to communicate back to you. I want to tell people not to judge what someone is like on the inside, by how they look on the outside.

Person Q:

I am a man in my mid 60's and I lived in Orient first and then an ICF, until my guardian helped move me into a house. I like my house and I like my staff. I go to a day program every day, where I like to sit at my table with my earphones on. I don't like loud noises and they make me angry. I am also blind so loud noises are difficult because I don't know where they are coming from. I like to talk to people especially pretty girls, but I don't like it when some people talk to me. They make me mad. [Those who work with this person always wondered how he knows what a pretty girl looks like, but we will take his word for it.] Sometimes I get mad, but my staff help calm me down. [Extreme physical aggression is not at all uncommon in people coming from institutions. They were mistreated for most of their lives and some have learned to protect themselves through aggression. This individual also learned many other bad habits in Orient that he still carries with him today. His vocabulary is quite colorful, and he has learned to call people some very derogatory names including the "n" word, which is ironic since he has never had sight.] I like food, and I like birds, but they won't let me have them because I snap their necks. [No one is really sure where this behavior came from but it is true. He would ask to have a bird, and then as soon as he got it, he would snap its neck. Unless it was just too noisy.] I am most happy now since I have my own house and people treat me nice.

Person R:

I am a young man in my 20's who has Muscular Dystrophy. I live with my aunt and she takes good care of me. I worked for the county board of DD for a while in an office, but I have become too weak, so now I go to a day program. I am extremely smart though and I am good with a computer. I actually speak German along with English, and I am writing a book of poetry in German. I want people to know that just because I am in a wheelchair, doesn't mean that I am not very smart and have a lot to offer intellectually.

Reference Page

All information provided in interviews was given by individuals who are receiving care through the Butler County Board of Developmental Disabilities.

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