

1-1-2019

Perceptions of Disability and the Truth: Breaking Barriers

Syeda A. Kirmani

Follow this and additional works at: <https://huskiecommons.lib.niu.edu/studentengagement-honorscapstones>

Recommended Citation

Kirmani, Syeda A., "Perceptions of Disability and the Truth: Breaking Barriers" (2019). *Honors Capstones*. 877.

<https://huskiecommons.lib.niu.edu/studentengagement-honorscapstones/877>

This Dissertation/Thesis is brought to you for free and open access by the Undergraduate Research & Artistry at Huskie Commons. It has been accepted for inclusion in Honors Capstones by an authorized administrator of Huskie Commons. For more information, please contact jschumacher@niu.edu.

NORTHERN ILLINOIS UNIVERSITY

Perception of Disability and the Truth: 4Breaking Barriers

A Capstone Submitted to the

University Honors Program

In Partial Fulfillment of the

Requirements of the Baccalaureate Degree

With Honors

Department Of

Educational Psychology

By

Syeda Asiya Kirmani

DeKalb, Illinois

May 11th, 2019

University Honors Program

Capstone Approval Page

Capstone Title (print or type)

Perception of Disability and the Truth: Breaking Barriers

Student Name (print or type): Syeda Asiya Kirmani

Faculty Supervisor (print or type): Hidetada Shimizu

Faculty Approval Signature:

Department of (print or type): Educational Psychology

Date of Approval (print or type): May 5th 2019

Table of Contents

Abstract.....	4
Introduction.....	5
Method.....	7
Stimuli and Observations.....	11
Procedures: People with Disabilities.....	11
Procedures: People without Disabilities.....	12
Results and Comparisons.....	14
Conclusions.....	16
References.....	18
Statistics of Disability.....	19
Written Open-Ended Survey	22

Abstract

Disability is a term that is used in many contexts, areas and walks of life. It has only recently started to be recognized. It is for this reason there are still many misconceptions regarding disabilities and the perception is rather skewed. It is for this reason there exists a rather large divide between disability, the truth and perception of it. The confusion and uncertainty of any fact creates a barrier between people with disabilities and people without. It is for this reason they often become isolated into their own group or culture like the deaf community.

In light of this, I have conducted a small study to investigate the possible divide and differences that exists between people with and without disabilities. Through this study, people in general may be better informed about such a divide. The purpose of the study is to try and understand this gap by shedding light into what the term disability means to different groups of people. The study hence compares the realities and perceptions that are prevalent between different groups of people regarding what it means to live with disabilities.

Keywords: Perceptions, disability, understand, differences.

Introduction

According to the Americans with Disabilities Act, an individual with a disability is a person with a mental or physical impairment. This impairment should at the very least limit one or more life activity (ADA, 2009). About 56.7 million people — 19 percent of the population — had a disability in 2010 with different severities and kinds of disabilities, according to the U.S. Census Bureau Reports in 2010 and the number has kept increasing since (U.S. Census, 2012).

According to the American Community Survey (ACS), an annual survey conducted by the U.S. Census Bureau, the overall percentage of people with disabilities in the US in 2016 was 12.8% (U.S. Census).¹ The population of people with disabilities occupy a distinct position in the United States location, society, economy, culture and education for their contributions to the society, people and culture as well as their roles in the policies and programs adopted by the government. People with disabilities bring exclusive sets of skills to the country as a whole, enhancing the definition of the word diversity. Disability is a mixture of life in which every person has a different level of function, response, role, purpose and meaning depending on societal, personal and environmental factors. The International Classification of Functioning, Disability and Health (ICF), is a classification of health-related area. It is a part of the World Health Organization context for calculating a person's health and disability. The ICF plans to overcome the issues, confusions, prejudice, many of these definitions by considering disability as a term for impairments, activity limitations, and participation restrictions. In 2016, the state with the lowest percentage of its population having a disability was Utah with 9.9%. The state with the highest percentage of disability was West Virginia with a percentage of 20.1% (Disability Statistics and Demographics, 2017).²

As the US population ages, the percentage of people with disabilities increases. In fact, there was less than 1% of people under the age of 5 years with a disability in 2016, for people ages 5-17 years the rate was 5.6% and for ages 18-64 the percentage was 35.2% (Disability Statistics and Demographics, 2017).³

The conditions to be considered a person with a disability are to have one or more of the six types: auditory/hearing, visual, cognitive, ambulatory, self-care, and independent living. From 2008 to 2016, the percentages of people with each type of disability have remained around the same. The percentage of people with ambulatory disabilities, cognitive disabilities, and independent living disabilities rose by 0.2 to 0.3 points over the period, while the rest of the categories rose by 0.1 point or less (Disability Statistics and Demographics, 2017). The aforementioned is a slight once-over concerning what disability is and what it means in regard to life in the United States and the people, society and culture here. The following study is an exploration of what the term disability means in today's society, what the response towards disability is, and how people who are classified as disabled are affected by the meaning. The study examines 5 families with a family member with a classified disability and 5 families without any members with a disability. The purpose of this study is to observe the differences in day to day activities and their views and opinions towards the other group.

Method

Participants

The study collected data from 10 families in total. In each of 5 families, there was a person with a disability. Out of 10 families, 4 were Angelo American, 2 were African American, and 2 were Asian American. The people with disabilities had an average age of 30.8 and the ages ranged from 23-43. Two out of the 5 families with members with a disability were living with their biological parents, 1 with a step-parent, and 1 with a single mother, and only 1 lived independently. The participants were all informed of the purpose, tasks, and expectations beforehand. All of the people with disabilities spoke English and only 1 spoke another language; Spanish. Each of the participants had at least a Baccalaureate degree. The people with disabilities had the following types, hearing impairment (deaf), speech impairment (stutter and nonverbal), cognitive impairment (autism), and physical impairment (spina bifida). All the disabilities listed here are from different categories and types. Although it was not orchestrated, having a person with disability from each type could give a better view or understanding about the definition and the categories of the term disability.

Procedures

Written Open Ended Survey and Responses:

Each family member who did not have a member with a disability was given a written open-ended survey at the beginning of the study. There were a total of 11 people who answered the survey. The questions were to understand the views of the families and what perceptions they held towards people with disabilities. The responses from these surveys were quite similar. There were 9 people in the “control group” believed that people with disabilities need help and are constantly dependent. Every single person who took the survey believed that a disability and a

handicap were the exact same thing. Out of 11 people, 8 said that independence for a person with disabilities is irrelevant because there is no point of trying not to be dependent. About 8 people also said that the most prevalent emotion they feel when they see a person with a disability is pity but no one feels like they need to do anything because they believe that a disability cannot be overcome.

Activities:

The responses were expected; the views regarding disability shown by the “control group” are unfortunately very common in today’s world. The reason for this study to see what the perceptions of the “control group” were and whether or not they can be changed. For this reason, I designed a course of activities that every person has to or has done at least a few times in their lives. The purpose of conducting these activities was to find out whether or not people with disabilities could take care of themselves independently, and subsequently to see whether the views the of “control group” were consistent with the actual competency of people with disabilities. Both groups were given the exact same activities, time limits, instructions and were evaluated by the same neutral people independent of this research. The activities were to be completed without any assistance or aid. The families were not to interfere unless absolutely needed or if the activities usually require their assistance. All the activities were simple and to the point. The activities were: cooking, cleaning up, solving some mathematical equations, writing a page or two on a given topic (conducting research for it), giving a short 15-minute presentation to a group of people on the previous activity, babysitting a child (with hidden supervision and no interference), and the last activity, writing a passage and reflecting on the past 5-10 years in life. All the activities were completed over a course of a couple of days.

The families of the participants were present for all the activities. They were generally administered in a naturalistic environment and incorporated in their everyday activities. Each person started with cooking a simple meal. The next activity was to clean up. The one thing that was not allowed in this activity was using the dishwasher. After the cleaning activity was to write a page or two on the topic “autonomous vehicles and their impact on transportation and safety”. They were each given 2 hours for research the topic so as to get a good understanding of the above topic. It was to be at least 300 words. The assignments were then graded by a neutral volunteer who was a teacher’s assistant and had background in grading assignments. There was a rubric that was made to evaluate the kind of responses the participants give, and each paper was graded accordingly. The next day the participants were given a total of 15 mathematical problems and 20 minutes each to solve them. There were 3 problems from basic algebra, 3 from trigonometry, 3 from precalculus, 3 from statistics, 3 from calculus, and 3 from linear algebra. Every single participant was introduced to these topics of mathematical calculations in their school and college days. The next activity was babysitting a child. The same child was used for all participants. She was 18 months old and her mother was one who helped observe in this activity. Every participant was well prepared for the activity. They were told the day before that they will be babysitting an 18-month-old girl and they each spent some time getting things ready for the child. The next activity was presenting the research they had done the previous day regarding “autonomous vehicles” to a group of people that volunteered for the activity. None of the participants knew the volunteers and they were given points on a rubric created for this activity. The rubric evaluated the content of the presentation, the way the content was presented, whether their argument was compelling enough (does it make the audience see their point regarding the autonomous vehicles), and whether the person was able to keep the audience

engaged and maintain all the rules of public speaking (eye contact, speaking slowly, not reading off cards/visual, etc.) The last activity conducted was writing a passage reflecting on their lives for the past 5-10 years. This activity was kept for the last to see the tone of responses. The point of this particular activity was to understand the participants with a disability and their response to their impairment/disability and the way they cope and live with it. The participants were asked to write about the activities they took part in and whether or not they felt not having a disability would have changed the way they participated in any of the activities. For the control group, it was to see their lives relative to a disability and what effect they think it would have had on their lives if they had a disability. They were asked to write about how they would have partaken in the activities with a disability and what changes they would see in themselves.

Every single activity was chosen not based on what effect it has on a person with a disability, but as activities that people without experience a lot in their day to day lives. All of the participants (with disabilities and without) have completed their Baccalaureate degrees; a few of them are currently in a Master's program and a couple have completed their Master's degree as well. Each participants' day to day activities (education and home) included cooking, cleaning, presenting, working on written papers, and mathematical problems (the areas of studies were engineering, software development, analytics, management technology, and physics). All the participants had nieces and nephews and they may have been put in a situation where they had to watch them due to any reason. The babysitting activity was also a way to incorporate a new but completely viable situation that may occur. The one reason for having this activity as a part of the study was to see whether a person with a disability could take care of another person when the situation required for it. After the completion of these activities, there was a general discussion regarding how the participants saw people without disabilities or people with

disabilities. After the conduction of all activities and after the results were shared between the two groups with their consent and then the written open-ended survey was administered again. This was done to see whether there was any change in the views and the perceptions of the “control group” regarding the people with disabilities after seeing that they were able to do everything they were asked to.

Stimuli and Observations

People with disabilities

There were 5 different dishes made; spaghetti with meatballs (nonverbal), egg strata (stutter), lasagna (deaf), casserole (autism), and pancakes (spina bifida). Each of the dishes were completely edible, delicious, and made with ease which demonstrated that the participants were comfortable with cooking them and have been doing so for a while. They all then had absolutely no problem cleaning up after cooking as well. Each of the participants were familiar with washing dishes by hand and in spite of their disabilities, nothing hindered them. Everyone was able to complete them easily. For the next activity, they all sat down for mathematical problems and were permitted the use of calculators. Every single participant was able to complete the task. All 5 participants were able to solve at least 10 problems correctly. The average was 12 and all the participants said that they guessed on only one problem. None of them required the full 20 minutes per problem. The babysitting activity was the most interesting one. Every participant had snacks ready for the child, had a separate area ready in case the child wanted to nap, activities like coloring, reading, block building, and some kids cartoons and shows ready in case they needed them. The child was slightly fussy that day, but each participant handled her expertly. Some ways were a bit different and not usually what one would associate with calming a child down, but they worked incredibly. One of the participants (autism) when saw the child was not

calming down decided to have a fun singing and karaoke session with the child. In the beginning, it did not seem like the child was happy with it, but she ended up enjoying and partaking in it. Three of the others (spina bifida, stutter, deaf) created different shapes with the blocks and kept coloring sheets everywhere for the child to use. The last participant (nonverbal) used bedsheets and pillows to make a fort throughout the living room. As we were informed, the child had never seen anything like that and was naturally curious. She also was not very familiar communicating with sign language or a simple AAC and the participant used it to their advantage. They used the curiosity of the child to distract her and keep her entertained till the mother took her back. The next activity was researching and writing a paper. All the papers were well written, properly thought out and professionally written. For the presentation, each of the participants did well presenting their research. They were able to get their point across. There were a few moments of stage fright, panic, and stuttering but they got over it in the first few minutes of presenting. They were confident in what they knew and what they presented and made a good or bad case regarding the response they had to the topic. The last activity that was conducted was done very well. There were a few times during the papers that there was some negativity regarding instances in their lives, but they dealt with it appropriately and had the help and support needed.

People without disabilities

The participants had made 3 omelets, 1 yogurt, granola and fruit bowl, and an egg and cheese sandwich. Like the last group, a dishwasher was not allowed, and every participant was to wash the dishes by hand. The food was all edible and delicious and was made with time conservation in mind. The participants knew their way around the dishes and had a sense of familiarity with cooking these particular items. All of them were able to do so and they admitted to making slightly simple dishes to save up on washing the dishes because they are not fond of

washing dishes. For the next activity, they were allowed the use of calculators as the previous group. The results were very similar to the previous group. Every single participant was able to complete the task and all 5 solved at least 9-10 problems correctly. The average was 12 as well but there was only one participant who guessed the answers. None of them required the full 20 minutes either. For the babysitting activity, all the participants prepared some board games, blocks, and books for the child. One of them also had some children's cartoon DVD's which they kept ready in case they needed it. They were all well prepared and ready for the child's fussiness. For the research paper, all the papers were written professionally and were well organized and well thought out. While presenting, only a couple of the participants had a slight case of stage fright and stammered for a bit before getting better and presenting more confidently. The rest of the participants presented flawlessly. They all put forth their point very well. One of the participants created a 3D visual to help the audience understand the details of the topic and used the model to try and prove the point they wished to make. The last activity or the reflection was to see how they see their last 5-10 years relative to a disability. This activity was conducted to try and understand what a person without disabilities thinks of a disability and what strategies they come up with to cope with and deal with a disability. Most of them were of the opinion that living with a disability would be the hardest thing to do. Only one person said that they would try to overcome the disability and not see it as a negative part of their life. The participant went on to mention someone they knew someone who had a stroke and due to that ended up with a speech impairment. This person never saw it as a bad thing but used the disability to their advantage and lived positively saying that you can't change anything now but only move forward. The participant found this attitude very encouraging and wrote that they would like to do the same if ever in a similar situation.

Results and Comparisons

As shown above, there were not many differences in the ways the two groups performed the activities and excelled at them. There were rubrics and guideline made for each task and each person was to follow a certain set of instructions. Each participant followed them as required. No one needed assistance or aid. There were a few noteworthy comments. The first group showed more creativity in responding to the activities. They all made dishes that are slightly more time consuming but delicious and pleasing to hear about. They used this activity to show that they don't just cook basic food but can make harder and more time-consuming dishes. For the second group, most of them mentioned that they were making simple dishes because it is easier to clean up and less time consuming to make and clean up. It made sense logically and was a good point made. For an everyday activity, less time to make and cleanup in the kitchen is usually required and needed. Although both groups performed tasks in different ways, they both demonstrated the reasons for doing so. The people with disabilities used this activity to show that they could make harder and more time-consuming dishes with relative ease while the "control group" showed that they choose to make simpler dishes to save time and effort on cleaning up after. The other activity which did strike was the babysitting. The first group came up with the most creative ways to deal with a fussy child especially given their disabilities. The nonverbal participant used sign language and the AAC device to distract the child from her fussiness and get her more involved into something else. The participant with autism sang songs and played with instruments to calm the child and it worked to entertain the child and make her happy. All the research papers were on the same level. The average score out of 50 was a 42 and the lowest was a 38. The presentations on the research were very well done and almost on par. The participant with a stutter gave a disclaimer of sorts informing the group that they stutter and to bear with

them. But all issues with the stutter were thrown out because the presentation was very nicely done. There was a visual aid and the points made were quite compelling. For the nonverbal participant, the AAC was used as well as a visual which had a speaking feature. The last activity was the reflection on their lives. All of the participants were very open, clear and truthful. There were moments of grief and sadness but no negativity. Every single one of the participants with disabilities were determined not to see their disability as a handicap but as an alternative way to see and live through life. They all make sure to use their disability to overcome problems they face instead of seeing it as an obstacle. All in all, I found creativity was very dominant among this group. When discussing this fact with some of the participants with disabilities, they said that they have to spend a lot of time trying to come up with different ways to do something and thinking outside the box is almost a compulsion to be able to find ease and comfort in day to day activities (Steven, 2019).

I also compared the views of the two groups. At the beginning of the study, a questionnaire was given to each participant and their families to see the views each group held regarding disabilities. The “control group” and their families had assumed that the participants with disabilities would not be able to complete all the task and not without help. They thought that they would need assistance for everything and could not be independent of help and support. They also felt that there were not many people with disabilities and that the people with them are given help regardless whether they needed it or not. Only one person in the control group had a different opinion because the participant worked with a woman with epilepsy and was able to see firsthand that a disability is not a handicap but merely a part of life for that person.

After the activities, they were given pamphlets and information on disabilities, the kinds, the types, the statistics and how they live along with their feelings and experiences. The

participants with disabilities assumed that people without disabilities were not aware of the challenges they face and when faced with someone with a disability, the only reaction they get is pity or sympathy. After the completion of the activities and the results of the activities shared, the families of the “control group” they were given the written open-ended surveys again. This time, most of the responses were constructive and respectful towards people with disabilities. There was one participant who said that although people with disabilities are able to conduct certain activities, they will not be able to conduct all activities normally. The participant made it clear that they were being objective not judgmental or critical, and merely stating a point. When this view was communicated to people with disabilities, they agreed completely. One participant mentioned (autism) that there is always something that they are not able to do, but that does not mean that they are dependent or reliant on others. They always face difficulties with a new task or with something particularly difficult, but then they would not be people *with* disabilities if they could do everything a person without disabilities does. The only difference is that they need to put more time and effort into making sure they can succeed (Clive, 2019). The participants with disabilities said that they want to be seen as an equal and as someone capable of being independent and making their own decisions and living life on their own terms, even it means that they need to put more time and effort than the average person.

Conclusion

Both the groups learned some things they were unaware of about the other, the “control groups” more than the other. The survey taken at the end had the same questions but the responses from the “control group” suggested shifts in their perceptions about people with disabilities. They saw the participants with disabilities as being able to do what they want and achieve their goals. They admitted to being more knowledgeable about the types of disabilities,

the statistics, and the reality of the lives of people with disabilities now that they have seen an interacted with people with disabilities. The participants in the study changed their perceptions over a course of a week because of the contact they had with disability. Learning first hand what with people with disabilities are capable of doing thus seems to be one of the most effective way to alter a non-disabled person's views and perceptions about the actual abilities of people with disabilities.

References

US Census Bureau Public Information Office (2016). U.S. Census Bureau Reports, U.S. Census Bureau.

Disability Statistics and Demographics (2017). Disability Statistic Annual report: Rehabilitation Research and Training Center.

Steven, S. (2019, March 21). Personal Interview

Clive, S. (2019, March 21). Personal interview.

Statistics of Disability

FIG 1. Percentage of People in the US with Disabilities, 2008-2016

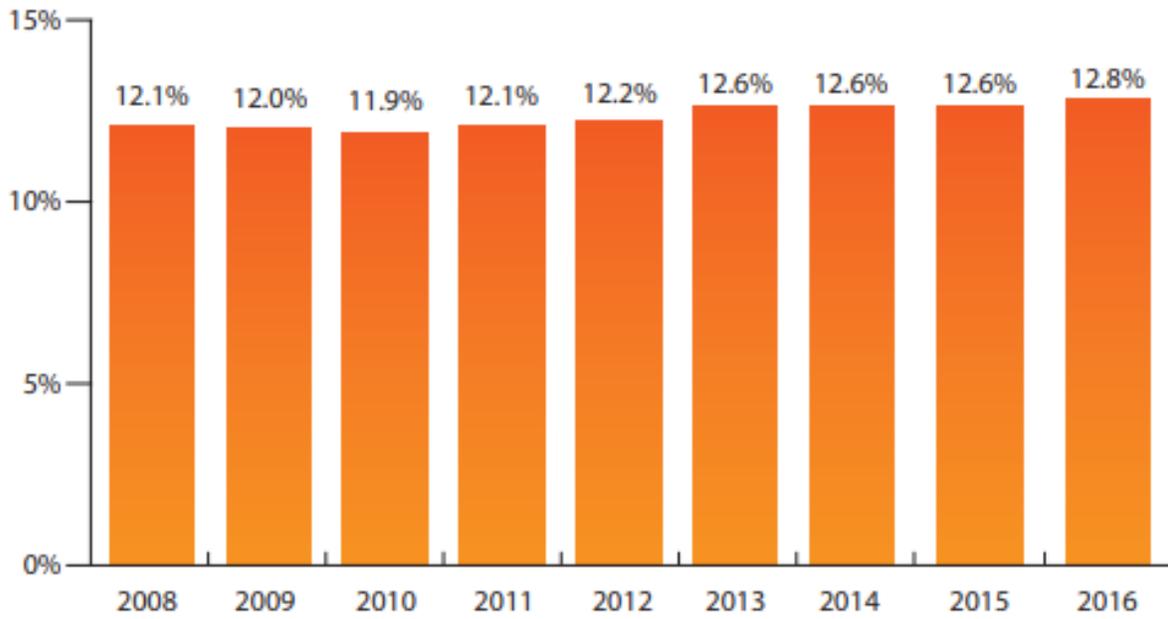


Figure 1.

FIG 3. Age Distribution of Disability in the US Population, 2016

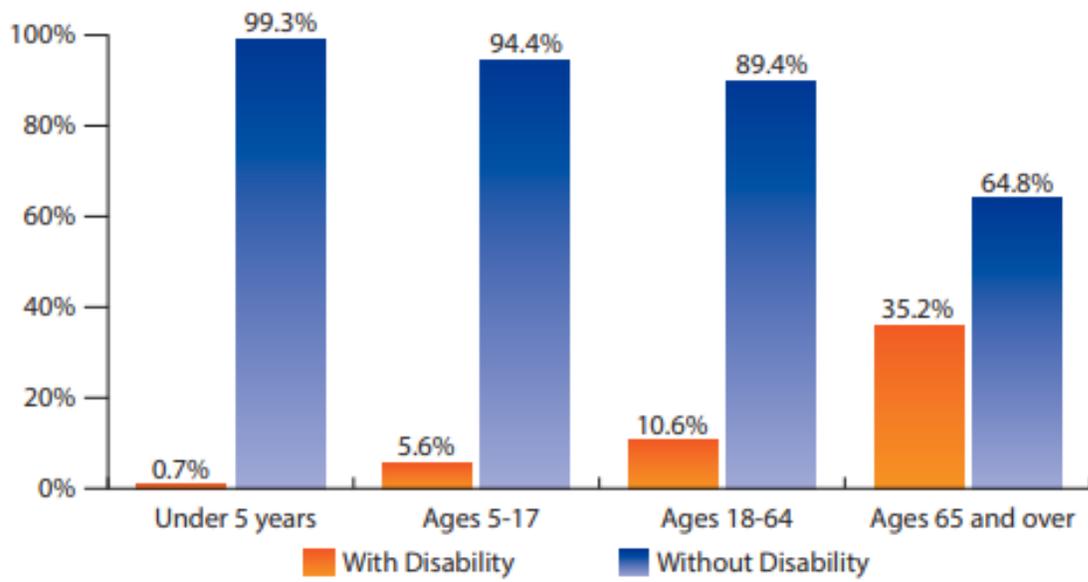


Figure 3.

Open-Ended Survey for the “Control Group”

1. What is a disability?
2. What is better to say; disabled or people with disabilities?
3. Who all are classified as people with disabilities?
4. What is a handicap?
5. Is a handicap the same as a disability?
6. Can people with disabilities be independent?
7. Why or why not?
8. What is independence relative to disabilities?
9. What do you do when you see a person with disabilities?
10. What is the most prevalent emotion about a disability?