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**Disability Culture
Through the Eyes
of College Students with
Varying Physical
Disabilities**



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+ **Re-defining Disability Culture Post-ADA**

- What we know
 - 54.4 million Americans who are disabled
 - Traditionally, disability culture has been viewed on a continuum (medical model → social model) (Oliver, 1983)
 - Present working definitions from Brown & Gill
- What we don't know
 - Does this still hold true today?
 - Demographics of college students today

+ **Paradigm Shift Post-ADA?**

- Not alone thinking that these previous models are outdated or in need of re-examination
- Albert, Bickenback, Gabel & Peters, Shakespere & Watson (from UK), but **notably even the UN Convention on the Rights of Persons with Disabilities** is connecting disability to human rights and dignity and identifies a distinct paradigm shift in thinking about disability

+ Other Considerations from Past Studies

- Lack of inclusion of people with disabilities in studies
- Timeframe of the studies is close to the passing of ADA
- Emphasis on one subgroup of disability rather than a more holistic approach
- My strategy: Focus on capturing the stories from people with various physical disabilities today.

+ Research Questions

- i. Do individuals recognize an identifiable disability culture at this university, if so, what does it look like?
- ii. What is the developmental trajectory of entering into disability culture?

+ Methodology

- i. Qualitative, participatory research methods
 - i. Observations
 - ii. 1-on-1 Interviews
 - iii. Document Analysis
- ii. Participants & Sample Selection
- iii. Researcher-subject relations
- iv. Settings

+ Considerations

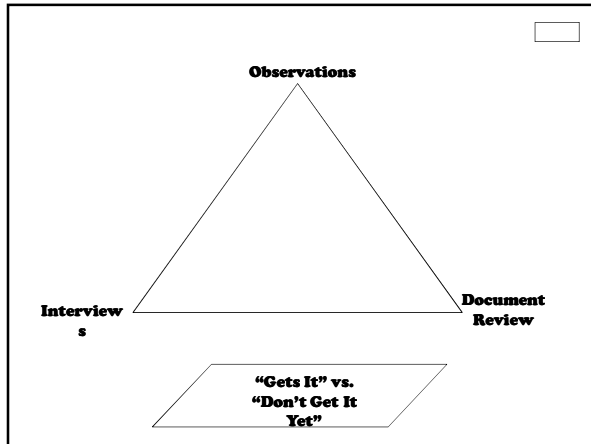
- Particular Setting Used
 - Setting is recognized as one of the pioneers for the disability rights movement, therefore the culture of this particular setting may have influenced the results of the study
- Disability Status of the Researcher
 - Care was taken in the recruitment of participants so as not to jeopardize

+ Sample Interview Questions

- What are the benefit(s) to this culture/community?
What are the drawbacks?
- Can you describe the kind of support (if any) do you get by associating with this community? Or, why do you not want to be associated with this community?
- Do you identify yourself as disabled? Why or why not?
- Are there identifiable subgroups within disability culture? In your eyes, what are they?

+ Data Analysis

- Grounded theory approach allowing themes to emerge
- Results
 - "Getting It" versus "Doesn't Get It Yet"
 - Developmental Trajectory
 - Characteristics of Disability Culture



+ Results

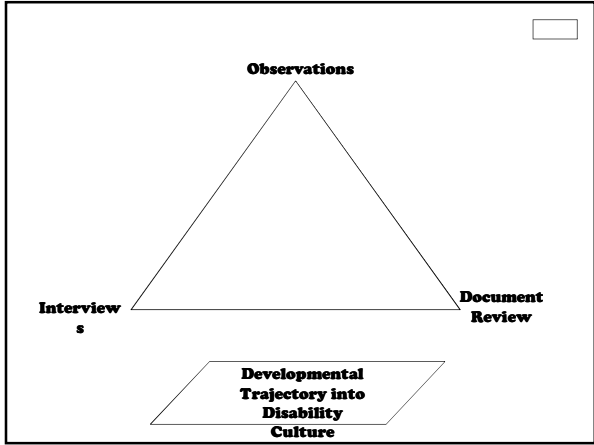
"Gets It"	"Don't Get it Yet"
<ul style="list-style-type: none"> • accepts own disability • comfortable around others with and without disabilities • is independent, capable of managing own care and does something for the larger population of disabled people 	<ul style="list-style-type: none"> • has not come to terms with disability • appears awkward or uncomfortable around others with disabilities • struggles with independence, hygiene perhaps overly reliant on others

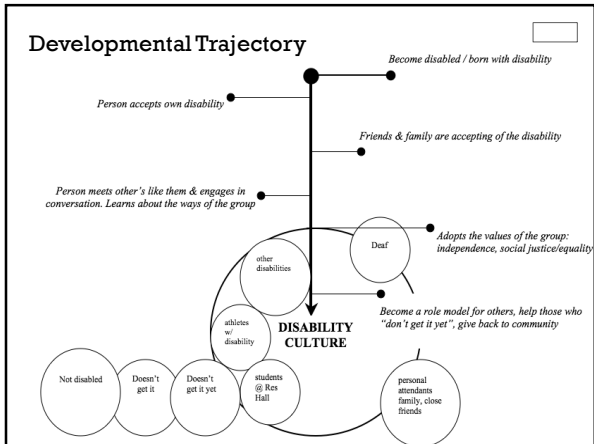
+ Example 1, Researcher Memo

• *The underlying premise is that the individual has either 1) not come to terms with their disability and are living in a fake illusion that they will someday get their old life back or 2) that they must accept all the negative stereotypes and accept help from everybody and lead a life having a pity party for themselves. "Doesn't get it" means that the individual is perhaps hateful towards other people with disabilities. There is a sense of resentment there because they do not want to associate with them, by ignoring them it means they are not really like them and that they can still get out of this world of disability. On the same token, the individuals who "get it" are the ones who are leading successful lives—they hold a job as opposed to living off of SSI income, they do something meaningful and constructive with their lives either by obtaining an education or through athletics or through community outreach or whatever. The individuals who "get it" are also the ones who carry the responsibility of reaching out to those who "don't get it yet" to assist them—to show them the ropes, to reassure them that it's okay to be frustrated about your disability at times, to laugh when certain mishaps happen and to make the most of it.*

+ Example 2, Observation Notes

• One individual was asked to reach out to a family of a young kid who was recently injured. XXX is currently still in rehab having only been injured about a month ago. XXX thought his future was set—to go to college to play collegiate football and wrestling on full scholarship. Then, disaster struck and his life as he once knew it was over. The family is still grieving this loss and struggling with coming to terms with the disability. The person who was requesting that the current wheelchair athletics coach call this kid up, said, “well you know, they just don’t get it yet, it’s all too new”. He then went on to say, “this is exactly what he needs right now though, is just to know that you’re out here and that there are people with disabilities who don’t piss on themselves and who are athletes and who have jobs.” XXX said the family seems ready, they are already laughing about stories that they have been told by XXX and they are ready to “get it”, they are willing to learn. They need to meet people to move on to that next step.



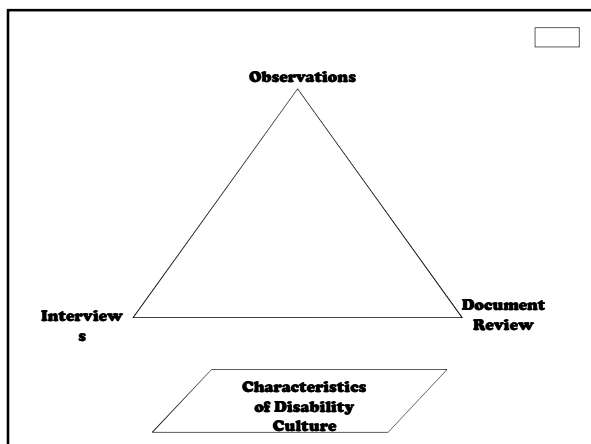


+ Interview Excerpts

- *"I did every day activities with able bodied people and I just adapted to it. I never limited myself...where there's a will there's a way and I found a way to accomplish what I wanted to do."* [person accepts own disability]
- *"Holy crap, there were a bunch of cripples! Before, I had only seen like three, I had never seen that many people like me before, it was intense."* [meeting others like you]
- *"I felt like wow, I remember feeling like wow, we're like all the same, we're connected"* [meeting others like you]
- *"The [wheel]chair gives you that comfort zone at first where you know that they have experienced similar situations to you so you have you can relate whereas someone who doesn't have a [wheel]chair might not be able to relate and as I also said earlier there is that initial awkwardness between an able bodied person and someone in a wheelchair because they don't know what they can say or do."* [meeting others like you]


+ Interview Excerpts (cont.)

- *"I think that coming to a university with a sports program, there is a bit of a split between the athletes and the non-athletes and then of the non-athletes and people with more hidden disabilities and those with more severe disabilities. I don't feel like those groups mesh as much."* [subgroups]
- *"I've never really been a part fully of either. It's been half Deaf, half hearing...but the hearing world pushes me to go back to the Deaf world, but the Deaf world does the same thing too."* [subgroups]




+ Themes of Disability Culture

- Independence
- Social Justice
- Giving Back to Others




+ Independence

- For those who use wheelchairs, measured by:
 - Ability to manage personal hygiene needs
 - Ability to navigate your world
 - Knowledge about your equipment
- For individuals who are Deaf, viewed as:
 - Ability to request own accommodations
 - Take charge of own disability
 - Ability to be a self-advocate



+ Independence Examples

- *"We talk about peeing and pooping at the dinner table, we do."*
- *"I love that we can just talk about this stuff, who else can you go up to and just flat out ask about cathing or pressure sores on your ass? It's great!"*
- *Observation Researcher Note: When witnessing new introductions, or meeting someone with a disability for the first time, the standard questions asked are always, 'what is your name, your disability and the type of equipment you use.'*
- *Document Analysis Note: On the form to request disability related accommodations it is expected that you can check off the type of equipment that you currently use and that the individual filling it out knows what all of the items are that are listed.*



+ Social Justice

- Mentioned by all interviewees, though the meaning of this term varied.
- Concept of equality still was prevalent, but interpretation was different.
- Strong sense of entitlement from the interviewees.

+ Social Justice Examples

- *"They just have to, it's the law."*
- *"You're denying a student with a disability the right to have their own room which is wrong; it goes against university policy for sure, and probably against ADA! Really??? Ugh, it just makes me so mad! But, I also feel like a second class citizen."*
- *"I don't think any of us [people with disabilities] today are looking to stage a revolution or a crusade, we're not ever going to chain ourselves to the courtyard steps like you hear about back in the day. What those people did before us was very important; it was because of their work then that we can be like this today. I can fight the battle if it comes up on my own, I don't need the power in numbers because most of my environment is accessible now. So, it's not that these issues aren't big deals or that there aren't things to improve on, it's just different now. It may only be one restaurant that isn't accessible, so I can just go to a different one."*

+ Giving Back to Others

- There is a civic duty associated with disability culture to help other people who may not get it yet, to reach out to young children with disabilities and to be a strong role model.

+ Giving Back to Others Examples

- *"As students and young adults with disabilities, I think we kinda **need** to be a role model and to take a stand."*
- *"I like telling my story, and I think things like this [participating in an interview] are fun... we have to do this kind of stuff, ya know? It's how people learn and how the younger generation with disabilities will grow up to be independent like us too."*
- *Observation Researcher Note: Giving back isn't always about being an actual mentor or coach, sometimes by being a member of a disability group outside of the walls of the University, or within you are actively involved in some way. Perhaps it's going back to a local hospital, or even simply living life and being willing to answer questions when they come up from a stranger in the grocery store or at the airport. It could be as simple as going to a student panel, or even answering an email.*



+ Revisiting Earlier Questions

- Disability culture *does* exist according to all the study participants, however, describing it was a challenge.
- Differences from earlier definitions and perceptions
- Similarities to earlier definitions and perceptions



+ Limitations of Present Study

- The uniqueness of this particular setting
- Only four participants in this current study
- Perspective from others (support staff, personal care attendants, family members, friends) is missing
- Time- would love to get more in-depth interviews with a broader range of participants



+ Future Research

- Expand the same study methodology and approach to include individuals with cognitive and/or learning disabilities
- For comparison purposes, repeat study at other community colleges/colleges/universities
- Exploration of other themes that emerged more directly (i.e., relationships)
- Case study of a newly injured individual to see if the developmental trajectory holds true
- Comparative qualitative study on the progression into Deaf culture versus disability culture

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