# Pilot Study: Understanding how DeafBlind People Make Meaning of their Avowed and Ascribed Identities

Deaf Studies Conference Transformations Proceedings

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## Abstract
*The purpose of this pilot study is to understand how DeafBlind people make meaning of their avowed and ascribed identities and how they navigate the medical-pathological descriptions used to define them. Phenomenology was used with Glickman's Deaf Identity Scale as a framework for this study. By conducting this study, the findings will provide insights on our identity, our culture, our perceptions on both how people perceive us, and how we perceive ourselves. Baumeister, Ashmore, and Jussim (1997) mentioned, "...the broader society assigns roles to the individual and shapes the values the person holds, so that identity is also an important means by which society can influence and control his or her behavior" (p. 191). How people perceive us can profoundly influence our discernment as a Deaf, DeafBlind, or DeafDisabled person.*

*There are two goals in this study: to share the findings with the DeafBlind community, and challenge the pathological view prevalent in studies regarding Deaf, DeafBlind and DeafDisabled individuals. These goals are achieved by providing culturally-based research from an emic standpoint revolving around the topics of DeafBlindhood. "In the study of cognition in organizations, and in social science more broadly, there are two long-standing approaches to understanding the role of culture: (1) the inside perspective of ethnographers, who strive to describe a particular culture in its own terms, and (2) the outside perspective of comparativist researchers, who attempt to describe differences across cultures in terms of a general, external standard" (Morris, Leung, Ames, & Lickel, 1999, p. 781). Since this study comes from researchers who are DeafBlind and Deaf-sighted respectively, this project is unique in the sense that it will come from both emic and etic views. Some ideas are borrowed from related findings on Deaf culture to justify the importance for this shift. "...Deaf epistemology relies heavily on personal testimonies, personal experiences, and personal accounts to document knowledge" (Holcomb, 2010, p. 471). This is supported by Napier (2002) who mentioned, "Of the various literature that has been written about the Deaf community, its language and culture, most of the works have discussed the notion of culturally Deaf people who identify as a member of the Deaf community as a linguistic and cultural minority group" (p. 141). Therefore, this project collected data from DeafBlind members justifying the need for documentations of testimonies, experiences, and knowledge of DeafBlindhood as a marginalized group.*

*Specific themes emerged from this study: medical, culture, socialization, language, community, and accessibility. Each theme was significant for how individuals identified themselves and where they stood regarding Glickman's scale. What stood out in this study were Glickman's marginal and immersion scales, and how the participants responded to external factors pertaining to their identity. These findings emphasize the need for more emic studies regarding deaf people with diverse identities that have been overlooked in numerous studies. In closure, with this type of research, both Deaf*

*Studies and DeafBlind Studies can participate in transformative work to improve connections among non-marginalized and marginalized communities.*

## Keywords
Deaf studies, deafblind, identity, language, community, accessibility

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## Presentation Transcript

Sarah Morrison: I'm Sarah. I identify as DeafBlind. That's enough about my identity for today's conference.

Najma Johnson: My name is Najma. I identify as Black DeafBlind. Right on!

SM: Yeah. So, I want to open with… Really, I find this setup awkward. I'm not used to it. Typically, I do this in a one-on-one setting. It's like when Deaf people go to hearing conferences, and they have to put up with looking back and forth between the interpreter and the presenter, right? For DeafBlind people, it's double, triple, even quadruple the work. It's a dissociating experience. I don't have vision. I don't have hearing. So yeah, I feel a major disconnection... and this set-up, I'm not too used to it. You want to add anything, Najma? I noticed some things when I came to the workshops this morning to observe. They talked a lot about oppression and the concept of injustice, communication access, and other things like that. It was interesting. So, I thought of three words relevant to this: audism, vidism, and distantism. So, I thought I'd grab this opportunity to touch upon those topics and explain why I'm here. Let me go back. I'm a bit overexcited, I need to hold off on that.  Really, why I've dived into this topic is because of the new research. I myself am a student at Lamar University. As I progressed through my studies, I wanted to focus on DeafBlind-relevant topics, but was taken aback by the inadequate information about DeafBlind identity, language, culture, community, and communication — I emphasize, DeafBlind. There was a plethora of research on Deaf people, on queer people, on Black people, on white people, and even religion. But where was the research about DeafBlind people? There's not enough. Nor are there enough researchers who themselves are actually DeafBlind. That's my goal for this project. I surveyed people — I noticed in my research that many referred to "Deaf" and "Blind," as two separate words rather than one, usually with a hyphen between the words, or with "Deaf" capitalized, but not "blind." There was a lack of uniformity in how the term was used. I wasn't satisfied with that, so I surveyed a total of 14 people. I found that one participant preferred the terms as separate terms, but the rest of the participants preferred a single term, with both words capitalized: "DeafBlind." Backtracking a bit, the point of this research project was to allow DeafBlind — culturally DeafBlind — individuals to determine for themselves how they wanted to identify themselves. That's where the words ascribed and avowed come in. "Ascribed" comes from the medical perspective. Say I'm a doctor. I take a look at someone and determine that the person needs a hearing aid or cochlear implant, and needs fixing. Or perhaps I determine that person is blind, and plaster all those labels on the person. That's ascribing — which stems from medical prescriptions in that I "scribe" your prescriptions. This is how society views and labels you. On the other side, we have

"avowed," which is when individuals autonomously decide how to identify themselves. That's why I opened with saying I was DeafBlind, while she identifies as Black DeafBlind. So that's the crux of our research work. Now, I want to add a message about the concept of different oppressions in research, but before we get into that, I want to go over the words "vidism" and distantism. I'll let Najma explain.

NJ: All right. Hello. Vidism has historically been defined as a visual barrier to access. Most of us know that. As time has gone on, I have come to a few realizations. Many people refuse to do tactile communication because they don't want to touch each other and prefer to have some distance between them. That means, when Deaf people see DeafBlind people, they often will leave. They will not even touch the DeafBlind people to inform them that they're leaving. Why don't they do that? Instead, they often will try to leave unnoticed, almost as if escaping. That was an interesting realization for me. So, a lot of what I see happening more frequently is "distantism," when people are reluctant or uncomfortable about touching each other in order to communicate. Oddly enough, Deaf people feel comfortable enough to tap each other on the shoulders and legs. There are many similarities — it's not the same, but there are similarities. The point is, communication is very visual with beautiful signing. But having to put your hand on someone else's hand while signing or even on another part of the body is something most people aren't eager to do. It's certainly painful. Many DeafBlind struggle to accept their identity as a result of this distantism. Vidism is a factor, yes, but distantism means a person who outright refuses to touch another person. They think, "I'll let others take care of it or let the interpreters figure it out." No. Do it yourself. If you want to communicate with us, touch us. That's the most important part of our identity.

SM: That was beautifully said. Related to research, a lot of sighted researchers have the option of filming interviews, and then analyzing, researching, and studying those videos. For me, I'm DeafBlind. I can't rely on film. I have to do it in person. That's one con about surveying. I have to have physical contact or have someone type their thoughts without assistance. After that, I did coding to find similarities and differences. The terms "vidism" and "distantism" were among the words that came up in relation to ignorance. That's a medical perspective, that we should be fixed. Going back a bit, now, let's visualize how vidism comes in as it relates to research. Research relies heavily on visuals, another language in society used by researchers. Another example I want to add for that word in my attempt to give you a better idea. How deaf people typically meet a hearing person is that person will tap on their shoulders and ask "Are you deaf? Can you hear me? No? You can't hear me? Oh, okay. Can you read my lips?" That's very similar with DeafBlind people and what we experience, when we are asked things like: "Oh, you can't see me?"

NJ: "Are my clothes okay? Are the colors okay? Can you see me? Am I clear? Should I stand farther away?"

SM: It's a similar concept, with vidism. It's annoying. Just go for it and start communicating. The attitude is a major part of that, too. "Oh, you're DeafBlind. Ahh! What do—" Right now, whose space is this?

NJ: I feel this space is for Deaf sighted people. That's how I honestly feel.

SM: Yeah, that's your space, for sighted people. We feel disconnected because we're not used to it. My kind of meeting, or workshop, tends to have three of us who touch each other, and she will be with three others. Najma and I will have up to three people each. After that, we switch. You now have an idea of what it's like for us —

NJ: I wish I could open this stage up to other DeafBlind people to come up and engage in ProTactile with us. I wish. It should be that way. It's psyching us out currently because this is a sighted area. It's disconcerting. It's hard. I hope that changes in the future.

SM: The reason for that is there are many issues related to the DeafBlind community right now, and there's a lot going on. There are many issues in Deaf Studies. This conference's theme is transformation, right? So now it is an opportunity for DeafBlind people. Where are we? We're still far behind. Deaf people are a long way ahead of us. Deaf people have access to interpreters, information, and research, and I think it feels like they're 20 or 40 years ahead of DeafBlind people. We're still lagging behind and we're constantly trying to catch up. We've been trying to get Deaf people's attention, but they keep leaving us behind, forgetting about us. So, it's really important issue for us to understand. I've started with identity, to have a better idea of where and what factors influence them to become a part of society. How does that affect future research with language? What is really important is DeafBlind identity. How did you come to identify as DeafBlind?

NJ: To make a long story short, I identified as retinitis pigmentosa (RP) in 2005 then Visually Impaired, or VI. When I came to Gallaudet in 2008, it was a strong signing community. But I continued to use the term VI for myself until 2014. I lived with a DeafBlind family during my internship and that changed my perspective. I called myself DeafBlind. I came back to Gallaudet after the internship and I graduated as a DeafBlind person. Why did I change that term? Because that family was fine with making mistakes, like breaking things and falling. They said "It's fine, it's okay. It's normal." They said we didn't have to follow societal views. They said, "That's how it is to be DeafBlind. Falling is beautiful!"

SM: That. Like she said, she lived with a DeafBlind family. That is her identity. What about me? I went to the Seabeck DeafBlind Retreat where I had the opportunity and honor to meet aj granda and Jelica Nuccio. These women are DeafBlind who started the ProTactile movement. I met them and from there on, my heart changed. I'm DeafBlind. Before, I wasn't sure. There are many similarities with Deaf people who have the common story of coming from a hearing family with no communication who finally find their home at a deaf school or college. They find that connection. They find that they're finally home. Now, going back a bit, based on this research, I used Glickman's Deaf Identity Scale as a framework for this study. That was what I used for this research project. It has — it's slipped my mind — yes, the medical view, the hearing scale. Next was the marginal scale, and immersion scale. Immersion by — sorry, my fingerspelling — the bicultural scale. I noticed that DeafBlind people tended to — I will ask them to go to the next scale.

NJ: The man over there is clicking through the slides, but there are technical issues.

SM: Okay, anyway, the point is, if you look at the factors — medical, social, and accessibility was the last one, I forget. The point is that from the medical view, that person identifies as Deaf-Blind with a hyphen. That relates to Glickman's model, which is the medical, hearing scale. It represents the belief that I must be fixed and follow the doctor's opinion. The doctor and audiologist are right and I must listen to them. They're always right. There's no self-decision-making going on, nor is there the concept of autonomy. I let them, or society, tell me what to do. As for the social aspect, there is one story I learned at a Seabeck event. One person said something cool. Are you familiar with the Harry Potter movies? Yeah? Perfect. Beautiful. It is common for DeafBlind people to use that analogy with wizards and muggles; muggles represent sighted people while wizards are DeafBlind people. Anyway, I used Glickman's model. Finally, I want to recognize that for me, personally, I recognize I'm on the immersion scale. That means I'm resistant to sighted people, and it means ProTactile — oh, I forgot to share what ProTactile means. Can you explain what ProTactile is?

NJ: It's fine. Go ahead and explain that. I'll explain about immersion.

SM: Say that again?

NJ: You talk about ProTactile, and I'll talk about immersion.

SM: Okay. ProTactile, PT for short — you're familiar with that, yes? Yes? Okay. PT, really, is a language. It's a language that Gallaudet did research on with Jelica Nuccio, aj granda, John Lee Clark, and Terra Edwards. There are others who were involved in that research who also tried to prove ProTactile is a language. Let me share a brief history. How many of you know about William Stokoe? He was a hearing professor, ironically, but that research holds parallels with ProTactile. History repeated itself, let's say, in the DeafBlind world. In the Deaf world, a hearing professor at Gallaudet proved ASL is a language, right? Terra, a hearing professor at Gallaudet tried to prove that PT is a language, too. Anyway, PT is becoming a strong part of our identity. Language does have an impact on your identity, just like how ASL resonates with Deaf people as a visual language. It is a huge part of the Deaf world. The DeafBlind world is closely connected with ProTactile and touch. Ben Bahan's presentation —

NJ: He's sitting right over there.

SM: Oh! There he is! He mentioned Earth for the hearing world —

NJ: [I love you, Ben!]

SM: — focusing on the ears. For the Deaf world, it's Eyeth, focusing on the eyes. But what about the DeafBlind world? What would it be? I've been thinking about it. And I came up with Touth? Something like that. We have to think about it. How do we remove the focus on only the ears and eyes? I've been playing around with words. That's my point.

We're so focused on those things. What about DeafBlind people? Many people, when they think of DeafBlind people, think of Helen Keller.

NJ: I don't like her.

SM: Why do you feel that way?

NJ: I'm sorry, I have personal feelings about Helen Keller. She's strongly tied to hearing people. She's orally dependent and depends a lot on SSPs, but DeafBlind people can be independent. All the attention is on Anne Sullivan. I applaud what they did, yes, but we often glorify her for the fact she was able to speak. It has nothing to do with the DeafBlind movement.

SM: Many of us forget about who the real pioneers are. There are two important DeafBlind people before Helen Keller we should know about, and I'll share a few names. One is Laura Bridge - I'm sorry, Bridgman. She went to Perkins School for the Deaf. However, know that there was a DeafBlind woman and I can't remember her name right now, but she went there at about the same time as Alice Cogswell. That was back when ASL originated. Was there any documentation about that DeafBlind girl? No. Yes, there was some, but it was brushed away and considered unimportant. Alice was glorified and she got all the attention. History shows that DeafBlind people have long been pushed aside. When Perkins was established, they asked Gallaudet to come work with Laura, but Gallaudet said no. They opened American School for the Deaf. How many of you know you know that? Now you know.

Andrew Biskupiak: I just wanted to let you know that there's ten minutes left for your presentation.

SM: All right.

AB: Sure.

NJ: Since there is ten minutes left, let me explain a little bit about immersion. I see the purpose of Glickman's model, but as a Black person, sometimes I resist. Sometimes I let down the walls I put up. The DeafBlind community is full of white people and it's hard to make connections with them. At Gallaudet, with Deaf people everywhere, I connect with any DeafBlind person. It's a relief, but when it comes to talking about culture, it can become an issue. I connect to the Black community, but it's difficult because of vidism and distantism. When I go back to the DeafBlind community, I face racism. I do see that it's important to talk about the identity model. I'm glad that Sarah started this. I'm happy to see that work. I hope to see more and more DeafBlind people of differing identities be a part of this work. Not just that, but also those who are LGBT, undocumented, disabled, and many more. There is a large DeafBlind community but the Deaf community decides whether you're worthy or not. I hope to change that.

SM: The goal of this research is to hopefully find more research about DeafBlind and collaborate with DeafBlind people like her and myself, not just those who are Deaf sighted. For example, Deaf people are sick of hearing people taking over. It's like, "Umm. We are just as qualified to

conduct research, too." It's time. It's time for a change, a transformation. That's the goal, for more DeafBlind people to be involved in research and to be part of DeafBlind studies or any disability studies with many different focuses. The point of this presentation is to open that door for more opportunities for DeafBlind researchers and DeafBlind participants, how to avoid any kind of visual means of research, like film, signing in public, and so on. Try to be more conscious about that when it comes to research.

NJ: I forgot to mention that I have a five-year-old Deaf grandchild. When it comes to PT — I should mention that he was a bit language-delayed and hadn't yet started signing fluently — and so we've been working with him. When he was finally ready, I put my hand on his hand, and he got so mad. He thought I was taking away his language. I didn't mean to do that. That was a new situation for me. Yes, I encourage ASL, and it is important. But for me, how can I communicate? When I put my hand on his hand, he got upset and said it was like I was biting his hand. He said, "No!" I tried to explain that I'm DeafBlind, but he said I could see a bit. My point is that schools strongly emphasize the visual language. It's beautiful and I agree completely, but he has three DeafBlind grandparents — me, and his other set of grandparents. And he still doesn't like our hands on him. So, what I did was I dropped him off at a babysitter with a DeafBlind person. That worked out just fine. That DeafBlind babysitter's rule is if you don't do PT, then you go home. He was caught off-guard by that, and is beautifully fluent at PT now.

SM: I like that. I'm thinking of what I was going to say. That really summarizes the point. We need more, we need more of a focus on identity and how DeafBlind people can have our own space. For me, Sarah, I am trying to open myself and move from that immersion to go back to being bicultural. Why do I say "go back"? Because I grew up hard of hearing. I had a hearing family. I was oral and mainstreamed. I went to ASD, and I found my deaf identity there. I went to RIT, and I became blind. I had to code-switch, uncomfortably so, so it's been an ongoing journey. I noticed that Glickman's model shifts. It doesn't stay the same. It is constantly shifting. Right now, I notice that I'm a mix of immersion, because I cherish PT with my DeafBlind identity, but at the same time, I want to incorporate all these other things. How do I do that? Let's wrap up. I think we'll wrap up.

NJ: While her research is important, I think it's also important to recognize that people have different visual barriers. Some identify as DeafBlind and that's fine. Some identify as VI. I hope we allow space to be open and let DeafBlind people go on that journey and discover their identities themselves. There aren't many DeafBlind role models. If sighted people welcome DeafBlind people and are ready to support them and touch their hands, that will make a change. We might let go of focusing on the beauty of it. ASL is beautiful, yes, but PT ASL is even better. I'm just letting you know. I promise. It's better. I promise. Just try!

SM: For sure. After this is finished, please go ahead and come up to us. We'll show you some PT. You'll be shocked. It'll blow your mind. It's really fantastic. For example, let me share a quick story. I chatted about PT training with kids with Jelica. They were cute kids in, I think kindergarten or first grade. One boy was very shy and timid. I told him I'm DeafBlind too and showed him something cool. I asked, "Do you like superheroes?" He said yes, and I asked him who he liked. He said he liked Spiderman. I said, "I'll show you something cool. Ready?"

I touched his hand and jumped with my fingers on his fist and moved it as if I was running and jumping on his arm and body, which represented Spiderman jumping on a building. He was so impressed and could completely connect to the concept. We did that back and forth and played. We really enjoyed that. He was really shy about it at first, and that's because of societal influence. Society says, "No touching. "It's not appropriate." But that is access. For you to do that, it takes away language access to thrive. Touching is not a bad thing. Think about your privilege. What is the sign for privilege?

NJ: If I see or touch "privilege" signed like that again, we're not talking anymore. That's a big no-no! Get rid of it!

SM: I don't like that sign either, but really, this is a lot more to cover in this topic related to DeafBlindhood. So much more.

NJ: That's annoying! Your sign annoyed me and I began using it. But I understand.

SM: Happy thoughts? Any happy thoughts?

NJ: As long as we're touching each other, I'm happy.

SM: Okay. I think that's it. If you have any questions, we will have an open floor at 4:30. If you "see" us with your privilege, please don't hesitate. Go ahead and talk to us.

NJ: Grab us. Touch us!

SM: We will be happy to answer your questions about this, all right? Thank you!

NJ: Thank you!

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